



AMANDA NAIDOO

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**THE DOCTRINE OF INFORMED CONSENT AND MANDATORY TESTING FOR
HIV: LEGAL AND ETHICAL IMPLICATIONS**

A Thesis

Submitted to the School of Law, in complete fulfilment of the requirements for the Degree of
Masters of Laws (LLM)

Written By

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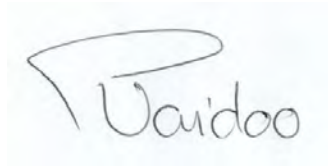
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DECLARATION STATEMENT

I, Amanda Naidoo, hereby declare that this dissertation is a product of my own work except where otherwise stated and expressly acknowledged, and that it has not been previously presented either in part or in its entirety at any other university for the award of a degree.

Signature_____

A handwritten signature in blue ink, appearing to read 'A Naidoo', is placed over a light blue rectangular background.

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DEDICATED

This thesis is dedicated to my husband Dhanandhran and my children Megan Claire and Brianna Rae who believed in me and who gave up many precious hours of our family time to enable me to complete this work.

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ABSTRACT

This paper investigates the doctrine of informed consent and mandatory testing with reference to the legal and ethical implications for HIV. The doctrine of informed consent is entrenched in South African law through the constitution, legislation and the common law. The doctrine provides that medical treatment can only be administered to a person if he has given informed consent according to certain requirements. These requirements have also been endorsed in the rules of medical professional bodies. The doctrine of informed consent is applied to testing for HIV and the rules to be followed when a person is tested for HIV. Recognition is given to the fact that there are exceptions to informed consent. These exceptions are examined, one of them being mandatory testing.

Mandatory testing is an exception to informed consent where the rights of a third party stand to be infringed. Due to the high HIV infection rate in South Africa, this paper examines whether there is a need to implement legislation for mandatory testing for HIV without the option to opt-out. Focus is placed on the need for testing with an opt-out option for all persons requiring medical treatment. This has to be done in the context of the constitution, legislation and the common law.

The impact that a mandatory testing policy may have on the freedoms and rights of the patient, is also investigated such as the right to privacy, confidentiality, and bodily integrity. This paper concludes that South Africa has the highest rate of HIV infection in the world and exceptionalism, poor uptake of voluntary counselling and testing and extensive informed consent rules have hindered progress in the fight against HIV/AIDS. This paper recommends opt-out testing for all persons requiring medical treatment, a multi-layered approach to HIV testing and a simplified informed consent process without compromising patient autonomy. The introduction of new laws for mandatory testing for HIV is not recommended as it is a violation of a person's constitutional rights and freedoms.

LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral treatment
ARV	Anti-retroviral
AZT	Azidothymidine
GRID	Gay Related Immunodeficiency Disease
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
NACOSA	National Aids Co-ordinating Committee of South Africa
NGO	Non-Governmental Organisation
PEP	Post Exposure Prophylaxis
PMTCT	Prevention of Mother to Child Transmission
SAMA	South African Medical Association
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
WMA	World Medical Association

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CHAPTER ONE

HISTORY OF HIV/AIDS

1.1 Introduction

This paper examines the doctrine of informed consent and mandatory testing for HIV. Reference is made to the legal and ethical implications of the doctrine of informed consent and mandatory testing for HIV. Legislation, case law and guidelines pertaining to HIV testing in general, are investigated with particular emphasis on opt-out testing for HIV. Mandatory HIV testing is defined and the current legislative position is discussed together with the guidelines prescribed by professional medical bodies such as The Health Professions Council and the South African Medical Association. Recommendations for future HIV testing in South Africa are made in the concluding chapter. This chapter sets out the origins and history of HIV and HIV testing. It also examines the history of HIV within the South African context. An outline of each of the chapters contained in this paper is set out thereafter.

1.2 History of HIV testing and counselling

HIV emerged in the United States of America in the 1980's as a disease that affected homosexual men and injecting drug users.¹ The disease was initially called the gay related immunodeficiency disease (GRID) or the "gay plague".² It was soon discovered however that the disease could affect anyone in society and was not confined to gay men and injecting drug users. This information caused a sense of panic to emerge and public information about the disease emphasized the dangers of the disease instead of providing information on how to manage or prevent it.³ Due to a lack of scientific data about the disease and the societal stigma attached to two groups of people perceived by society as living an immoral lifestyle, HIV/AIDS was treated with great caution and much emphasis was placed on the obtaining of informed consent for testing.⁴ Gay rights advocates and societal groups began to put pressure on government to

¹ KM De Cock, D Mbori-Ngacha & E Marum „Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century" (2002) 360 *The Lancet* 68.

² JH Smith & A Whiteside „The history of AIDS exceptionalism" (2010) 13 (47) *Journal of the International AIDS Society* 2.

³ *Ibid.*

⁴ KM De Cock et al *op cit* 68.

prioritize the disease as a human rights issue in view of the possibility of societal discrimination and homophobia. There were fears that if people were afraid of being stigmatized, they would be afraid to be tested and would, as a result not receive treatment.⁵ It was thus that AIDS exceptionalism came to be born.

1.2.1 HIV and Exceptionalism

Lazzarini in writing about exceptionalism stated that in the early days of the disease, HIV was considered so different and exceptional that it prompted health officials to hold the view that HIV policy should also be unique with a civil liberties approach instead of a „traditional approach“. Some of the reasons given for exceptionalism were that the disease was contracted through intimate sexual contact, there is no cure for it and it could take a long time for the disease to manifest itself.⁶

A debate began focusing on the importance of protecting the human rights of the individual versus the public health benefit. This debate saw the emergence of thinking which questioned the value of HIV testing and counselling. Some believed that HIV testing and counselling did little to help the individual whilst there were others who believed that testing and counselling could help change behavior.⁷ Judge Edwin Cameron questioned whether exceptionalising the disease was actually hindering and undermining the human rights of individuals with HIV and whether the rules and medical requirements surrounding the diagnosis and treatment of HIV only served to further propagate stigma and discrimination.⁸

1.2.2 Voluntary Counselling and Testing

The World Health Organization called for caution in extending testing beyond blood donors and international consensus was reached that testing had to be voluntary. Unlike diseases such as

⁵ JH Smith & A Whiteside „The history of AIDS exceptionalism“ (2010) 13 (47) *Journal of the International AIDS Society* 2.

⁶ E Cameron. Normalising Testing - Normalising AIDS. Ronald Louw Memorial Campaign: Get Tested, Get Treated. Forum lecture. Durban: University of KwaZulu-Natal 4th May 2006, P4.

⁷ R Baggaley, B Hensen, O Ajose, KL Grabbe, VJ Wong, A Schilsky, Y-R Lo, F Lule, R Granich & J Hargreaves „From caution to urgency: the evolution of HIV testing and counselling in Africa“ (2012) 90 *Bulletin World Health Organisation* 652.

⁸ E Cameron. „Normalising Testing - Normalising AIDS“ Ronald Louw Memorial Campaign: „Get Tested, Get Treated . Forum lecture Durban: University of KwaZulu-Natal 4th May 2006 P 4.

Tuberculosis and Malaria which could pose a public health risk, HIV did not pose such a threat and there was accordingly no justification for relaxing informed consent rules. In order to test a person for HIV, written informed consent was required. The reason given for requiring consent was that HIV could not be treated and people who tested positive could face discrimination from others in society.⁹ This gave rise to the concept of voluntary counselling and testing.¹⁰ Voluntary counselling and testing is defined as:

The process by which an individual undergoes counselling enabling him or her to make an informed choice about being tested for HIV. This decision must be entirely the choice of the individual and he or she must be assured that the process will be confidential.¹¹

Voluntary counselling and testing takes place where individuals themselves attend a health facility to seek HIV testing and counselling. It involves pre-test information sessions conducted either individually or in a group and is followed up with individual or couple post-test counselling. This process must ensure informed consent, counselling and confidentiality.¹²

The process of voluntary counselling and testing (VCT) should empower the individual to make the choice for himself and must guarantee that the information exchanged during this process would be confidential. The person can only be empowered by information given in the form of counselling. HIV counselling is a confidential dialogue between a trained counsellor and the person. During this dialogue the person and the counsellor will discuss the personal risk of HIV, ways in which infection may be prevented, the emotional and social issues linked to infection. This counselling process is crucial in helping the individual to decide whether or not to test for HIV and to cope with the stress of testing.¹³

⁹ CH Coleman, MJ Selgelid, A Reis, LB Reichman & E Jaramillo "The role of informed consent in tuberculosis testing and screening" (2012) 39(5) *European Respiratory Journal* 1057.

¹⁰ R Baggaley, B Hensen, O Ajose, KL Grabbe, VJ Wong, A Schilsky, Y-R Lo, F Lule, R Granich & J Hargreaves „From caution to urgency: the evolution of HIV testing and counselling in Africa"(2012) 90 *Bulletin World Health Organisation* 652.

¹¹ UNAIDS Technical update. Voluntary Counselling and Testing (VCT) May 2000 P3.

¹² South African Department of Health National HIV Counselling & Testing (HCT) Policy Guidelines March 2010 P15.

¹³ UNAIDS Technical update: Counselling and HIV AIDS. November 1997 P3.

The challenges around voluntary counselling and testing arose due to the low uptake by individuals. Due to the voluntary nature of the process, a person has to present for testing and counselling before he or she can be aware of his/her status. The testing and counselling process is comprehensive and consent has to be expressly given.¹⁴ Fear of stigma and discrimination are deterrents to accessing testing as people are afraid of these possible consequences and therefore fail to test.¹⁵ Failure to test means that fewer people know their status and fewer people access treatment thereby thwarting efforts to reduce infection rate. Hence the view arose that these factors only serves to foster exceptionalist thinking and treatment of the disease thereby impeding progress in reducing infection and providing access to treatment. Judge Cameron argued that people refused to test because the consent and counselling requirements actually served to treat HIV as a „different and distinct“ disease which led to it being thought of as abnormal, horrible and exceptional.¹⁶ Although HIV can be managed and treatment, by the time people did access treatment, they were too sick for treatment to be effective.

These challenges eventually highlighted the need for a new approach to testing, but one within a legal and human rights framework. As a result there was shift from voluntary counselling and testing towards an opt-out approach to testing. In 2007 the World Health Organisation recommended the implementation of opt-out testing in settings with high HIV prevalence to all adults accessing health care facilities.¹⁷ During opt-out testing a patient will be offered a routine HIV test unless he or she declines. In this way more people can be tested and can access treatment if found to be HIV positive.

Although opt-out testing has also been plagued with some controversy and is viewed by some as being „tacitly mandatory“, it does go some way towards eliminating exceptionalism and allowing people to know their status and make treatment and lifestyle choices.

¹⁴ E Cameron. Normalising Testing - Normalising AIDS. Ronald Louw Memorial Campaign: Get Tested, Get Treated. Forum lecture. Durban: University of KwaZulu-Natal 4th May 2006, P5.

¹⁵ D McQuoid-Mason „Routine Testing for HIV-ethical and legal implications“ (2007) 97 (6) *SAMJ* 416.

¹⁶ E Cameron. Normalising Testing - Normalising AIDS. Ronald Louw Memorial Campaign: Get Tested, Get Treated. Forum lecture. Durban: University of KwaZulu-Natal 4th May 2006, P5.

¹⁷ See Paragraph 4.5.1

The advantages and disadvantages of opt-out testing as well as other testing options will be discussed in greater detail in Chapter 4.¹⁸

In summary voluntary testing and counselling was introduced as a response to the initial concern about management of the disease. Although informed consent is express and comprehensive and ensures the protection of the rights of the individual, it can also be viewed as impeding testing and access to treatment as well as fostering exceptionalism and stigma. As a result it became necessary to examine other options for testing, which have been outlined above and will be discussed in Chapter 4.

1.3 The South African context

1.3.1 Background

In 2009 it was estimated that of the 33, 3 million people worldwide living with HIV, 22 million were in sub-Saharan Africa.¹⁹ The disease was initially concentrated in Central African countries. However recent studies show that infection levels have declined somewhat in these countries but have increased rapidly in Southern African countries such as South Africa, Zimbabwe and Swaziland.²⁰

1.3.2 History of HIV/AIDS in South Africa

In 2003 an estimated 21,5% of South Africans between the ages of 15-59 were HIV positive and a thousand people were dying each day of AIDS.²¹ The early history of HIV was that the disease was spread by gay men in South Africa which caused people to think that it was a homosexual disease. However the disease soon began to spread through heterosexual sex and by 1991 the number of heterosexual cases equalled the number of homosexual ones.²² Currently the disease in South Africa is spread mainly through heterosexual transmission and is believed to be linked to poverty, poor education levels and transport links such migrant workers and truck drivers.²³

¹⁸ See Paragraph 4.5.

¹⁹ HY Fan, RF Conner & LP Villarreal *AIDS Science and Society* 7 ed (2014) 118.

²⁰ Fan, Conner & Villarreal *op cit* 119.

²¹ N Nattrass *The Moral Economy of AIDS in South Africa* (2004) 19.

²² Avert History of HIV/AIDS in SA. Available at <http://www.hivsa.com/static/hiv-aids-insouthafrica> Last accessed on 2014/07/03.

²³ Nattrass *op cit* 20,26 & 30

At present South Africa has 6,3 million individuals who are living with HIV, with a 19 % prevalence rate in the 15 to 49 year age group.²⁴ There are approximately 3,5 million women aged 15 and up who are living with HIV.²⁵ These statistics imply that more than half of those infected South Africans are women which would include pregnant women as well. The greater the number of HIV infected pregnant women implies that there will be a greater number of HIV infected children.²⁶

Such staggering statistics should have made HIV testing and treatment policy a governmental imperative. It should mean that all stakeholders such as government, non-governmental organisations (NGOs), health care industry, community and religious forums actively engage to reduce the risk of transmission and motivate for greater access to treatment and testing in South Africa. Pregnant mothers and babies should also be prioritized. However, although South Africa has more resources than other African countries it has been frighteningly slow to respond to the epidemic.²⁷

The history of HIV policy in South Africa has been fraught with controversy due to a lack of political will, feelings of mistrust during political transition from the old apartheid regime to the new democracy in 1994 and political mismanagement.²⁸ In the late eighties and early nineties HIV/AIDS began to receive attention on a national level but the fledgling democracy appeared to be ill equipped to deal with the rapid spread of the disease and the need to take an aggressive stance to combat further spread of HIV and AIDS. The government instead cited other issues such as job creation, housing and education as priorities.²⁹

Despite the formation of the National Aids Co-ordinating Committee of South Africa (NACOSA) in 1992 and the National Aids Plan, progress in the fight against HIV was slow. Political leaders of the time such as President Thabo Mbeki and health minister at the time

²⁴ UNAIDS. South Africa HIV and AIDS estimates (2013) Available at <http://www.unaids.org/sites/default/files/epidocuments/ZAF/pdf>. Last accessed on 2015/03/17.

²⁵ *Ibid*

²⁶ Fan, Conner & Villarreal *op cit* 120.

²⁷ N Natrass *op cit* 29, 41.

²⁸ N Natrass *op cit* 41.

²⁹ Avert History of HIV/AIDS in SA. Available at <http://www.hivsa.com/static/hiv-aids-insouthafrica> Last accessed on 2014/07/03.

Manto Tshabalala Msimang questioned whether HIV did indeed cause AIDS and whether anti-retroviral treatment was helpful in stemming the spread of the disease. In a television interview following the State of the Nation address in 2004, Thabo Mbeki argued that AIDS is not as serious a problem as we think.³⁰ Manto Tshabalala Msimang was known to have said that the drug called azidothymidine (AZT) weakened the immune system and led to mutations in babies.³¹ Aids denialism continued until President Thabo Mbeki stepped down as President in 2008. In more than a decade this debate, denialism and inaction on the part of government meant that many lives were lost, many were denied access to treatment and little was done to wage war against the spread of HIV/AIDS. Life expectancy in South Africa declined from 61 years in 1990 to 49 years in 2009. This was largely due to HIV.³²

In 2003 Botswana rolled out the first universal access programme in sub-Saharan Africa. South Africa eventually bowed to international pressure and announced its public treatment programme in 2003.³³ Internationally the World Health Organisation (WHO) implemented its 3x5 campaign which aimed to provide access to treatment to 3 million people by 2005.³⁴ Change in governmental thinking and response to the epidemic came in 2009 when President Zuma acknowledged that South Africa has a serious HIV/AIDS problem that impacts individuals, communities and South African society. He went on to announce important changes to the national AIDS prevention and treatment programme. Pregnant women would be able to access anti-retroviral treatment (ART) at 14 weeks instead of 24 weeks. All HIV positive children under the age of one year would be eligible for ART regardless of their cluster differentiation four (CD4) count. President Zuma also announced the roll out of a national testing programme aiming to test and treat 15 million people for Tuberculosis by 2015.³⁵ In 2011 all HIV positive patients with a CD4 count of less than 350 would be eligible for ART. This was finally in accordance with the World Health Organisation (WHO) guidelines.³⁶

³⁰ A Van Niekerk & LM Kopelman (eds) *Ethics and AIDS in Africa The Challenge to our Thinking* (2005) 2.

³¹ N Natrass *op cit* 49.

³² Fan, Conner & Villarreal *op cit* 120.

³³ JH Smith & A Whiteside „The history of AIDS exceptionalism“(2010) 13 (47) *Journal of the International AIDS Society* 2.

³⁴ *Ibid.*

³⁵ Y Pillay, C White & N McCormick „How times have changed-HIV and AIDS in South Africa“(2012) 102 (2) *SAMJ* 77.

³⁶ *Ibid.*

Current research indicates that the number of people on ART has increased, more HIV treatment sites have been established and more nurses are able to initiate patients on treatment.³⁷ HIV infections have been reduced by about a third during the period 2004 to 2012 and since 2009 the government has initiated a scale up of HIV testing and treatment programmes where about 2,2 million people were seen to be accessing HIV treatment programmes.³⁸ While South Africa has made progress in its fight against HIV/AIDS and have committed to providing testing and treatment for its people, these successes should not overshadow the fact that there are still many obstacles facing us. Obstacles such as violence and inequality in our society, stigma and discrimination, poverty, gender inequality, lack of jobs, an ailing health system with shortage of anti-retrovirals (ARVs) in certain provinces, poor morale and lack of accountability of health workers in public health care facilities will no doubt have an effect on transmission, infection and mortality rates.³⁹

In summary the history of HIV globally as well as in the South African context began with pandemonium, uncertainty and panic and has been fraught with different views and ideologies. Initial uncertainty about the spread of the disease and the manner in which it should be approached medically, ethically and socially has been debated extensively. The remaining challenge globally is to find the most workable solution to the remaining challenges outlined above. This paper will explore whether there is a need to relax the rules of informed consent in favour of mandatory testing for HIV. Is there a need to make testing for HIV compulsory in a country which has the highest rate of infection in the world? On the other hand will a mandatory testing policy represent a gross violation of human rights and freedoms and be unjustifiable? Finally perhaps there is a middle-ground approach to testing and treatment that will allay fears of trespassing of rights as well as concerns that current approaches to testing do not achieve the goals set by national policy and guidelines.

³⁷ C Bateman „Activists warn: Don’t fall victim to our HIV successes” (2014) 104 (2) *SAMJ* 98.

³⁸ UNAIDS New HIV report finds big drop in new HIV infections in South Africa. Available at <http://www.unaids.org/en/resources/presscentre/featurestories/2014/january/20140117southafrica> Last accessed on 2015/03/17.

³⁹ *Ibid.*

1.4 Chapter Outline

Chapter 2 of this paper focuses on the legal aspects of informed consent. Informed consent is defined and the rules of informed consent are examined with reference to legislation, case law and guidelines where these rules may be found.⁴⁰ The four requirements for informed consent are discussed in detail and the chapter concludes with the challenges faced in implementing the rules of informed consent with reference to informed consent in HIV testing⁴¹.

Chapter 3 examines the ethical aspects of informed consent. The development of informed consent within the medical profession both globally and in South African is highlighted⁴² and the ethical guidelines of professional bodies for informed consent are discussed.⁴³

Chapter 4 focuses on an examination of the legal and ethical rules of informed consent when carrying out HIV testing. The sources of guidelines for HIV testing have been laid down in the constitution, legislation, case law, the guidelines of the Health Professions Council of South Africa (HPCSA⁴⁴), the South African Medical Association (SAMA) guidelines⁴⁵, and policies by government. This chapter also addresses the various types of testing options for HIV as well as the challenges encountered with certain types of testing.⁴⁶ Progress has been made in the area of HIV testing and traditional VCT is slowly being replaced by new methods of testing such as community testing and the recent introduction of self-testing kits. The impact of these new methods of testing on the rules of informed consent will be considered.

Chapter 5 examines the exceptions to informed consent implying instances when the rules of informed consent may be relaxed. The exceptions that will be discussed are emergency treatment, public health risk, therapeutic privilege, necessity and unauthorized administration⁴⁷, . Mandatory testing for HIV is defined and introduced as an exception to informed consent.⁴⁸

⁴⁰ See Paragraph 2.2.

⁴¹ See Paragraph 2.5.

⁴² See Paragraph 3.5

⁴³ See Paragraph 3.6

⁴⁴ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2007).

⁴⁵ SAMA *Ethical and Human Rights Guidelines on HIV and Aids Part A: General Principles* (2006)

⁴⁶ See Paragraph 4.5.

⁴⁷ See Paragraphs 5.2-5.5.

⁴⁸ See Paragraph 5.6.

Chapter 6 involves a detailed discussion of mandatory testing. The legislative provisions for mandatory testing are examined, highlighting some of the anomalies surrounding compulsory testing for HIV in sexual offences.⁴⁹ HIV testing in the employment context, and for pregnant women are also highlighted.⁵⁰

Chapter 7 is the concluding chapter of this paper. It provides a summary of the discussion in Chapters 1 to 6 and makes recommendations on the way forward for HIV testing in South Africa.

1.5 Conclusion

This chapter introduced the topic of HIV/AIDs. It explored the history of HIV testing and counselling by examining when the disease emerged within our society as well as the perceptions and initial thinking around the disease and affected groups. Voluntary HIV testing and counselling was defined and discussed with regard to the requirements for informed consent and with reference to pre-and post-test counselling. The emergence of exceptionalism and how it impacts testing and treatment was debated, concluding that the Voluntary Testing and Counselling process engenders exceptionalism and there is a need to embrace new approaches to testing. The history of HIV in South Africa was discussed with reference to how the political context influenced the rate of infection and the delay in access and treatment of the disease. Chapter 2 will focus on the legal aspects of informed consent. The discussion will examine the rules of informed consent within the Constitution, legislation and case law.

⁴⁹ See Paragraph 6.2.

⁵⁰ See Paragraph 6.3.

CHAPTER 2

LEGAL ASPECTS OF INFORMED CONSENT

2.1 Introduction

The aim of this chapter is to examine the legal aspects of informed consent by firstly examining the meaning of „informed consent“ which is central to the topic of this dissertation. Secondly the rules of informed consent are identified in sources of South African law such as provisions of the Constitution, National Health Act and the Consumer Protection Act. Having regard to the common law, the dual nature of the doctor-patient relationship and the requirements of the maxim „*violens non fit iniuria*‘ are discussed together with an exposition of the requirements for informed consent which were laid down in *Castell v De Greeff*⁵¹. A detailed analysis of the four requirements for informed consent which were laid down in *Castell*’s case is undertaken and other cases, both pre- and post- *Castell* are discussed to determine how the courts dealt with the issue of informed consent. The final part of this chapter focuses on the challenges experienced with the implementation of the rules of informed consent.

2.2 Definition of Informed Consent

The definition of informed consent ranges from the very simple to the very complex. Albert Jonsen et al defined informed consent as

The willing and un-coerced acceptance of a medical intervention by a patient after adequate disclosure by the physician of the nature of the intervention, its risks and benefits as well as of alternatives with their risks and benefits.⁵²

Informed consent is defined in the National Health Act as a situation where a person with legal capacity gives consent to be provided with a specified health service. This person must be informed according to the provisions of section 6 of the Act prior to giving his or her consent.⁵³

⁵¹ *Castell v De Greeff* 1994 (4) SA 408 (C).

⁵² RR Faden & TL Beauchamp *A History and Theory of Informed Consent* (1986) 282.

⁵³ The National Health Act 61 of 2003 s 7(2).

In *Castell v De Greeff*⁵⁴ consent was defined as a situation where the patient has knowledge and appreciation of the nature and extent of the harm or risk and consents to the harm or risk as well as its consequences.⁵⁵ The elements of this definition will be discussed in greater detail under the common law later in this chapter.

The person giving consent must have the legal capacity to do so.⁵⁶ Strauss states that knowledge and appreciation are two basic elements of consent and that a patient has not legally consented unless s/he knows what s/he is consenting to.⁵⁷ The above definitions provide an indication of how informed consent takes place and ideally places the patient at the centre of the process by giving him or her ultimate responsibility of giving consent after receiving the necessary information.

2.3 Informed Consent and Legislation

The rules of informed consent have also been laid down in the Constitution as well as in fairly new legislation such as the National Health Act and the Consumer Protection Act. These Acts ensure recognition and protection of the patient's human rights, and aim to redress historic imbalances by providing all people with the right to access health care, and the right to challenge a breach of the doctor-patient relationship and the rules of informed consent.

2.3.1 The Constitution of 1996

The Constitution Act of 1996 makes reference to informed consent in the provisions of the Bill of Rights in Chapter 2. Section 12 of the Act provides that every person has the right to bodily and psychological integrity which includes the right to security in and control over his or her body as well as the right not to be subjected to medical or scientific experimentation without his or her informed consent.⁵⁸ It follows that these rights which are entrenched in the Constitution must also be observed and respected for the purposes of obtaining consent in a medical setting. The Constitution and the rights entrenched therein serve as the backdrop for the recognition of the patient's rights to autonomy and self-determination when receiving medical care or

⁵⁴ *Castell v De Greeff* supra at 425.

⁵⁵ MA Dada & DJ McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 8.

⁵⁶ *Ibid.*

⁵⁷ SA Strauss *Doctor, Patient & the Law* 3rd ed (1991) 8.

⁵⁸ The Constitution Act 108 of 1996 s 12 (2)(b) & (c).

treatment. Dhai and McQuoid-Mason identify an autonomous person as someone who „has the ability to deliberate about personal goals and to act under the direction of such liberation.“⁵⁹ McQuoid-Mason also defines autonomy as a situation where the patient is „informed, independent and respected.“⁶⁰ The recognition and respect for the patient’s rights is crucial when obtaining informed consent. Such recognition is a concerted move away from the days of paternalism towards a patient centered, more inclusive approach to the doctor-patient relationship.⁶¹ The Constitution does however provide instances when a patient’s rights may be limited provided that such limitation is reasonable and justifiable and takes into account certain factors such as the nature and extent of the limitation as well as its importance.⁶² This paper will investigate whether mandatory testing for HIV can amount to a reasonable and justifiable limitation of the patient’s rights, or whether it will imply a violation of the patient’s constitutional right to privacy and to bodily and psychological integrity.

2.3.2 National Health Act No.61 of 2003

Prior to the implementation of the National Health Act, The National Patients’ Rights Charter was formulated by the Department of Health and launched by the Minister of Health.⁶³ Although the Charter is not a legally binding document, it was launched in 1999 to serve as a guideline to people seeking health services, as well as to health institutions concerning the rights and duties of people in the health sector.⁶⁴ It provides for informed consent in decision making by stating that everyone has a right to be given full and accurate information about the nature of one’s illnesses, diagnostic procedures, the proposed treatment and risks associated therewith and the costs involved.⁶⁵

The guidelines in the National Patients’ Rights Charter are similar to those mentioned in the National Health Act and the Health Professions Council of South Africa’s (HPCSA) guidelines

⁵⁹ A Dhai & D McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 70.

⁶⁰ D McQuoid-Mason „Michael Jackson and the limits of patient autonomy“ (2012) 5 *SAJBL* 11 Available at <http://www.sajbl.org.za/index.php/sajbl/article/view/191/176> (Accessed on 2013/07/18).

⁶¹ D Giesen „From Paternalism to self-determination to shared decision making“ (1988) *Acta Juridica* 116 Available at <http://heinonline.org>. Last accessed on 2013/07/25.

⁶² The Constitution Act 108 of 1996 s 36.

⁶³ Health Professions Council: *National Patients’ Rights Charter* Booklet 3 (2008).

⁶⁴ AIDS Law Project and Lawyers for Human rights *HIV/AIDS and the Law: A Resource Manual* 2ed (2001) 497-499.

⁶⁵ *Ibid.*

and also have as part of its mission, the realization and protection of the patients' rights to access to health care as well as to privacy and a healthy and safe environment.⁶⁶

In line with the Bill of Rights and the Constitution, the National Health Act was passed in 2003 with the aim of implementing a national health system which provides for the realization of the right of every citizen to access health care services and to redress past imbalances in the provision of health care services.⁶⁷ The Act specifically deals with informed consent and these provisions of the Act are dealt with further on in this paper.

For the purposes of clarity, the term „user“ in the Act is defined as „the person receiving treatment in a health establishment...“ and the term „health care personnel“ is defined as including health care providers and health care workers.⁶⁸ Informed consent is defined in the Act as „consent for the provision of a specified health service given by a person with legal capacity to do so and who has been informed according to the provisions of section 6.“⁶⁹

Section 6 of the Act provides that when a user is informed of his or her health status, the health care provider must:

- (a) Ensure that the user is given such information in a language that s/he understands;
- (b) Take into account the level of literacy of the user when explaining their health status;
- (c) Explain the range of diagnostic procedures,
- (d) Explain the treatment options that are available to the user, and the benefits, risks, costs, and consequences that are attached to each option.
- (e) Inform the user that s/he has the right to refuse such health services and inform the patient of the implications and risks associated with such refusal.⁷⁰

Whilst the doctor does not have to disclose every conceivable risk s/he must at least inform the patient of the serious or material risks in the proposed treatment.⁷¹

⁶⁶ *Ibid.*

⁶⁷ The National Health Act 61 of 2003 (preamble).

⁶⁸ *Ibid.*

⁶⁹ The National Health Act s 7(2).

⁷⁰ The National Health Act 61 of 2003 s 6 (1) & (2).

Section 7(2) of the Act provides that a health care provider must take all reasonable steps to obtain the user's informed consent.⁷² The Act does allow for certain exceptions, one of them being therapeutic privilege, in that it provides that the health care provider is allowed to deviate from the rules of informed consent in instances where disclosure of the patient's health status would not be in his or her best interests.⁷³ The other exceptions to informed consent will be dealt with later on in this paper. It is evident that the Act echoes the guidelines for informed consent laid down in *Castell's case*.⁷⁴ South Africa, being a country with people from diverse cultural and socio-economic backgrounds, the Act goes a step further to require that the language preference as well as the level of literacy is taken into account when obtaining a user's informed consent.⁷⁵

2.3.3 The Consumer Protection Act No.68 of 2008

The vague so-called blanket consents which require the patient to waive his or her rights and to indemnify the doctor or hospital against any loss or injury that may be sustained are contrary to the provisions of the new Consumer Protection Act.⁷⁶ As a result engagement and consultation before consent is central to the informed consent process. The Consumer Protection Act provides that a supplier (doctor) must not provide services to a consumer (patient) on terms that are unfair, unjust or unreasonable.⁷⁷ Any agreement which purports to be a waiver of the consumer's (patient's) rights or which seeks to indemnify the supplier from liability for loss due to gross negligence is prohibited.⁷⁸ McQuoid-Mason has argued that such clauses may be invalid and even unconstitutional.⁷⁹

⁷¹ Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* 14.

⁷² The National Health Act 61 of 2003 s7(2).

⁷³ Section 6(1)(a).

⁷⁴ *Castell v De Greeff* supra at 425.

⁷⁵ The National Health Act 61 of 2003 s 6(2).

⁷⁶ The Consumer Protection Act 68 of 2008 s 48 (1) (c) (i).

⁷⁷ Section 48 (1) (a)(ii).

⁷⁸ The Consumer Protection Act 68 of 2008 s 51 (b)(i) & s 51 (c)(i).

⁷⁹ D McQuoid-Mason „Hospital exclusion clauses limiting liability for medical malpractice resulting in death or physical injury: What is the effect of the Consumer Protection Act?“ (2012) 5 (2) *The South African Journal of Bioethics & Law* 67.

A doctor must take pains to ensure that the consent obtained from the patient is comprehensive as the Consumer Protection Act may be a basis upon which the patient can seek redress in the event of failure to procure proper informed consent from the patient. A doctor will not be able to rely on a blanket consent which seeks to waive the patient's rights or to indemnify the doctor against loss or injury. The doctor must ensure that the patient gave his or her consent to the proposed treatment and to the consequences that may arise.

2.4 Informed Consent and the Common law

Our Common law as well as that of other jurisdictions provides important guidelines on the doctrine of informed consent.

2.4.1 The doctor-patient relationship

Contractual relationship

The doctor-patient relationship is largely governed by the Constitution, legislation as well as the common law. Informed consent is central to the doctor-patient relationship.⁸⁰ The doctor-patient relationship can be seen as having two facets. The first is that it is a contractual relationship. The foundational principles of any contractual relationship imply that the parties are in agreement with the contents of their contract and that they have knowledge and appreciation of all the terms and conditions by which they agree to be legally bound to each other. The doctor and patient agree that the doctor will diagnose the patient's ailment and will provide treatment in accordance with acceptable medical procedures. The doctor is obliged to discuss all proposed procedures with the patient and must obtain the patient's consent to treatment.⁸¹ The patient is obliged to present him/herself for treatment and whilst the doctor cannot force the patient to submit him/herself for treatment, the patient can be held liable for lost fees incurred by the doctor.⁸²

The nature of their contractual relationship is such that the doctor does not have a right to treat the patient and the patient has to consent to any treatment by the doctor. The only exceptions are

⁸⁰ P Carstens & D Pearmain *Foundational Principles of South African Medical Law* (2007) 877.

⁸¹ MA Dada & DJ McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 5.

⁸² Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 6.

in cases where the patient is in an unconscious or semi-conscious state or where statute dictates that a person must submit to treatment for example where there may be a public health risk.⁸³

Duty of Care

The second facet of this relationship is of a fiduciary nature where the patient trusts that the doctor acts in his/her best interest.⁸⁴ It follows that a doctor who agrees to treat a patient must exercise a duty of care towards the patient and the patient must accordingly consent to such treatment by the doctor.⁸⁵ In exercising a duty of care, the doctor is only bound to treat the patient with the amount of skill, competence and care which may reasonably be expected from a doctor in that branch of medicine.⁸⁶

Once again a doctor cannot treat a patient unless the patient consents to such treatment.⁸⁷ Treatment without consent can lead to civil and criminal liability on the part of the doctor. The exceptions to this rule are where public interest considerations override the need to obtain consent from the patient to treatment or where therapeutic privilege or necessity (including emergency situations) can justify a deviation from the requirement of obtaining informed consent.⁸⁸

Consent therefore means that a patient agrees to accept a health-care service after being informed about the nature, effect, consequences and risk of such a service.⁸⁹ Van Oosten identified the purpose of informed consent. He stated that the purpose of informed consent is to ensure that the patient's right to self-determination and freedom of choice is recognized⁹⁰ and to encourage rational decision-making.⁹¹ These will be examined in greater detail during an examination of the requirements for informed consent.

⁸³ SA Strauss *Doctor, Patient & the Law* 3rd ed (1991) 3.

⁸⁴ A Dhai & D McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 70.

⁸⁵ SA Strauss, *Doctor, Patient & the Law* 3rd ed (1991) 3.

⁸⁶ *LAWSA* Vol. 17 (1999) para 30.

⁸⁷ Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 7.

⁸⁸ Carstens & Pearmain *Foundational Principles of South African Medical Law* (2007) 916, 917.

⁸⁹ Dhai & McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 71, 72.

⁹⁰ Van Oosten LLD thesis 446; cf Carstens & Pearmain *Foundational Principles of South African Medical Law* 883

⁹¹ *Castell v De Greef* (1994); cf Van Oosten Carstens & Pearmain *Foundational Principles of South African Medical Law* 883.

The maxim „*violent non fit inuria*“ which originates from Roman and Roman-Dutch law means that a willing person is not wronged. The principles set out in this maxim are recognized in South African law and bear reference when determining whether a person has given informed consent to medical treatment.⁹² A person who consents to the risk of harm cannot later claim damages if s/he were to suffer harm. The person’s consent renders the doctor’s treatment lawful and consent is therefore a valid defence to such an action for damages⁹³. Such informed consent must be obtained either when the person is giving consent for medical treatment or for the doctor to make a diagnosis.⁹⁴

In order for the defence of „*violent non fit inuria*’ to operate the defendant must prove that there was valid consent by the plaintiff. The requirements for a valid consent are:

- a) The plaintiff must have indicated that s/he was willing to suffer the harm or run the risk of harm occurring;⁹⁵
- b) Consent must have been given in an obvious manner;⁹⁶
- c) Consent must have been given before the harm occurred;⁹⁷
- d) Consent must be given by a person who is capable of expressing his/her will and is the person who suffered the harm;⁹⁸
- e) Consent must have been given freely and voluntarily;⁹⁹
- f) The plaintiff must have had full prior knowledge of the nature and extent of the harm or risk¹⁰⁰ and appreciated the nature and extent of the harm or risk;¹⁰¹
- g) The consent must be lawful, in other words it must not contravene statute or the legal convictions of the community.¹⁰²

⁹² JC Van Der Walt *Delict: Principles and Cases* (1979) par 33, 34.

⁹³ M Beard „Therapeutic Privilege and Informed Consent: A justified erosion of patient autonomy“ (2005) 68 *THRHR* 52.

⁹⁴ D McQuoid-Mason „An Explanation of Informed Consent“ Available at :<http://www.livingwill.co.za/consent.htm> Last accessed on 2013/6/18.

⁹⁵ M Loubser, R Midgley, A Mukheibir, L Neising and D Perumal *The Law of Delict in South Africa* (2010) 159.

⁹⁶ *Ibid.*

⁹⁷ M Loubser et al *op cit* 160.

⁹⁸ *Ibid.*

⁹⁹ *Ibid.*

¹⁰⁰ *Ibid.*

¹⁰¹ JC Van Der Walt *Delict: Principles and Cases* par 34.

¹⁰² M Loubser et al *The Law of Delict in South Africa* 161.

- h) There must be materialization of the risk which was foreseen, appreciated and assumed by the plaintiff¹⁰³.

The requirements for the defence of '*violent non fit inuria*' are also applicable to cases involving consent to medical treatment and these requirements were applied in *Castell v De Greeff*¹⁰⁴ where the court said that consent can be defined as a situation where the patient has:

- a) Knowledge of the nature or extent of the harm or risk;
- b) Appreciates and understands the nature of the harm or risk;
- c) Consented to the harm or assumed risk; and
- d) The consent is comprehensive and extends to the entire transaction, inclusive of its consequences.¹⁰⁵

Castell's case echoes the requirements for '*violent non fit inuria*' by clearly formulating the requirements for informed consent. In order to understand informed consent in its entirety, it is important to understand each of the elements of the above definition.

2.4.2 The requirements for informed consent

2.4.2.1 The patient must have knowledge of the nature and extent of the harm or risk

It is maintained that the doctor-patient relationship is an unequal one as the doctor is an expert in his field. S/he possesses the knowledge and experience relating to the patient's medical condition. S/he is aware of the risks and dangers inherent in any proposed treatment or procedure. The patient on the other hand is often a lay person with little or no medical knowledge. S/he is dependent on the advice and expertise of the doctor.¹⁰⁶

It follows that as a doctor cannot lawfully treat a patient unless the patient consents to such treatment; there is a duty on the doctor to provide the patient with all the information relevant to the proposed treatment or procedure in order to place the patient in a position to give real

¹⁰³ JC Van Der Walt *Delict: Principles and Cases* par 34.

¹⁰⁴ *Castell v De Greeff* supra at 425.

¹⁰⁵ Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 8.

¹⁰⁶ F Van Oosten *The Doctrine of Informed Consent in Medical Law* (1991) 22.

informed consent.¹⁰⁷ The doctor has a duty to disclose to the patient information relating to the nature, purpose, benefits, probable risks and consequences of the procedure or treatment.¹⁰⁸

Should the doctor fail to provide the patient with such information, any consent subsequently obtained cannot be regarded as informed consent. The actions of the doctor in treating the patient without such informed consent can render him or her contractually, delictually or criminally liable.¹⁰⁹

Some of the questions that arise in relation to the doctor's duty to disclose is how much information must the doctor provide to the patient? What amount of knowledge or information disseminated to the patient will fulfill this requirement for informed consent? Initially, the amount of information that should be disclosed was left to the discretion of the doctor. This was referred to as the „professional community standard“. ¹¹⁰This has since been replaced with the „reasonable patient“ standard which involves the patient playing a central role in the obtaining of informed consent.¹¹¹

In the early case of *Lymbery v Jefferies*¹¹² Wessels JA was of the view that a doctor need not meticulously point out all the possible complications to the patient. The doctor only had to provide the patient with a general idea of the consequences.¹¹³ In the subsequent case of *Rompel v Botha*¹¹⁴, Naser J stated that the doctor is obliged to inform the patient of the „serious risks“ that may occur and if the patient is not informed of such risks, then the implication is that any consent obtained is not valid.¹¹⁵

In *Castell's* the court concluded that a doctor is obliged to warn the patient of any material risks in the proposed treatment.¹¹⁶ The facts of the case briefly were that the plaintiff had undergone a

¹⁰⁷ Van Oosten *op cit* 22, 23.

¹⁰⁸ Van Oosten *op cit* 59.

¹⁰⁹ Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 7.

¹¹⁰ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 71.

¹¹¹ *Ibid.*

¹¹² *Lymbery v Jefferies* 1925 AD 236.

¹¹³ *Ibid.*

¹¹⁴ *Rompel v Botha* 1953 (unreported).

¹¹⁵ *Ibid.*

¹¹⁶ *Castell v De Greef* *supra* at 426.

subcutaneous mastectomy following the recurrence of breast lumps and a family history of breast cancer. The Plaintiff suffered complications post-surgery and claimed damages from the defendant on the grounds that the defendant had failed to conduct the operation with the professional skill required of a specialist plastic surgeon and that he had failed to warn the plaintiff of the material risks and complications that might follow from the operation as well as procedures that might minimize the risk.¹¹⁷

The court held that a medical practitioner has a duty to warn a patient of the material risks inherent in treatment or surgery.¹¹⁸ „Material risk“ was defined in *Castell's* case where it was said that a risk is material „if a reasonable person in the position of the patient if warned of the risk would attach significance to it; and a medical practitioner should reasonably be aware that the patient if warned of the risk would attach significance to it“.¹¹⁹ The information that is given to the patient should then place him or her in a position to decide whether s/he wishes to go ahead with the procedure or treatment or to refuse such treatment or procedure on the basis of the information provided to him or her.

The court also considered the question of when the duty to warn arises and what should be the nature and extent of the warning. In other words does a doctor have a duty to warn the patient of every conceivable risk or complication? Doctors may find themselves in a difficult position if they disclose too little to the patient. They could later be guilty of assault, however if they disclose too much the patient may be afraid to proceed with the treatment or surgery. These questions led to a debate between the patient's right to self-determination and freedom of choice and the doctor's duty to disclose. In *Castell's* case the court decided that the subjective patient-centered test for disclosure should be used.¹²⁰ This means that a doctor should disclose all information that a reasonable person in the patient's position would attach significance to.¹²¹ The

¹¹⁷ *Castell v De Greef* supra at 413.

¹¹⁸ *Castell v De Greef* supra at 426.

¹¹⁹ *Castell v De Greef* supra at 426.

¹²⁰ *Castell v De Greef* supra at 420J, 421C-D & 427 D-E.

¹²¹ RBritz & A le Roux-Kemp „Voluntary informed consent and good clinical practice for clinical research in South Africa: ethical and legal perspectives“ (2012) *SAMJ* 747.

subjective patient centered test was endorsed in the subsequent cases of *Broude v McIntosh*¹²² and *McDonald v Wroe*¹²³.

The court a quo had accepted the „reasonable doctor test“ formulated in *Richter v Hamman*¹²⁴. This test however was rejected in *Castell's* case where the court stated that this was a doctrine that did not receive much attention in South African law. This test was similar to the *Bolam* test¹²⁵ that was applied in *Sidaway v Bethlehem Royal Hospital Governors & Others* where the court was of the view that the standard of care required by a doctor was a matter of medical judgment.¹²⁶ The *Bolam* test states that a doctor is not negligent if he acts in accordance with a practice accepted at the time as proper by a reasonable body of medical opinion even though other doctors adopt a different practice.¹²⁷ The *Bolam* case was criticized in *Castell's* case on the basis that the standard of care required of a medical practitioner should be decided by a court and not by medical opinion.¹²⁸

The court in *Castell's* case considered the views of Giesen who examined the position of other common and civil law jurisdictions which were moving away from a „professional standard of disclosure“ towards a more „patient-based approach“.¹²⁹ Giesen suggested a blending of what he called two „patient based standards“. He stated that the objective or reasonable patient standard is one in which one would ask what disclosure should be made to the „reasonable patient“ in the position of the patient. The second subjective standard would involve an enquiry into the information that should be disclosed to the „individual patient“ taking into consideration his/her individual circumstances. The court in *Castell's*¹³⁰ case went on to say that in South Africa the issue is treated as one of consent to injury and the assumption of an unintended risk and not one of negligence due to a breach of a duty to care. Further, in order for the defence of consent to apply, the requirements for informed consent were set out.¹³¹ In *Castell's* case Ackermann J

¹²² *Broude v McIntosh and others* 1998 (3) SA 60 SCA.

¹²³ *McDonald v Wroe* 2006 All SA 565 C.

¹²⁴ *Richter v Hamman* 1967 (3) SA 226 CI.

¹²⁵ *Sidaway v Bethlehem Royal Hospital Governors & Others* 1985 L All ER 643 (HL).

¹²⁶ *Ibid.*

¹²⁷ *Castell v De Greef supra* at 424.

¹²⁸ *Castell v De Greef supra* at 425.

¹²⁹ *Castell v De Greef supra* at 421.

¹³⁰ *Castell v De Greef supra* at 425.

¹³¹ *Castell v De Greeff supra* at 421.

recognized the move towards protection and endorsement of the individual rights of the patient by saying: “It is in accord with the fundamental right of individual autonomy and self-determination to which South African law is moving”.¹³²

In summary, the patient must be informed of the nature or extent of the harm or risk. The duty to inform the patient rests on the doctor and the information provided must be comprehensive enough to enable the patient to make a sound decision on whether to consent or not to consent to the treatment or procedure. Failure to provide the requisite amount of information can lead to civil and or criminal liability on the part of the doctor unless s/he can prove that the risk was too remote or that one of the exceptions mentioned above apply. The principle that the patient must knowledge of the nature and extent of the harm or risk will be discussed further in the context of HIV in Chapter 4.

2.4.2.2 The patient must appreciate and understand the nature of the harm or risk

This requirement for informed consent is of critical importance. It is pointless for the doctor to provide the patient with information concerning the treatment or proposed medical procedure if the patient is unable to comprehend or understand the meaning of such information or its implications for his or her condition. Van Oosten points out that the information must not merely be received by the consenting party, but it must also be understood by him or her.¹³³ These two words „received“ and „understood“ provide the crucial link between the first two requirements for informed consent. Informed consent cannot be said to be achieved if a patient simply receives the information. S/he must be able to understand it and use this information to make a choice as to whether s/he will provide his or her consent to the envisaged treatment or procedure.

This sentiment was endorsed by Bekker J in *Esterhuizen's case* when he stated that in order to establish the defence of „*volenti non fit inuria*‘ the plaintiff should not only have perceived the danger but he or she must have appreciated it fully and consented to it.

¹³² *Ibid.*

¹³³ Van Oosten *The Doctrine of Informed Consent in Medical Law* (1991) 24.

How does one define understanding and appreciation? When can it be said that the patient has adequate comprehension of the information given to him or her? Further, the giving of consent is an autonomous and individual act and consideration must be taken of the fact that each individual possesses a certain level of intelligence, literacy and comprehension. How does a doctor know that a patient understands and appreciates the information since one patient's level of understanding may not be the same as another's?

Faden and Beauchamp define understanding as follows:

A person has a *full* or *complete* understanding of an action if there is a fully *adequate* apprehension of all the *relevant* propositions or statements (those that contribute in any way to obtaining an appreciation of the situation) that correctly describe (1) the nature of the action and (2) the foreseeable consequences and possible outcomes that might follow as a result of performing and not performing the action.¹³⁴

Carstens and Pearmain state that the foundational requirements for lawful consent relate to knowledge, appreciation and acquiescence on the part of the patient. The patient in turn must have the mental capacity to legally consent.¹³⁵ The issue of capacity is vitally important to this process and is discussed under the next requirement for consent.

It appears then that the patient must obtain a comprehensive appreciation of the nature of the action or treatment, and the consequences that may arise both in relation to performing the procedure and if it were not performed.

It is worthy to note however that Strauss cautions that "over informing" a patient could lead to a situation of not informing the patient at all.¹³⁶ This can occur where the doctor provides too much information that may be too technical and beyond the comprehension of the patient.¹³⁷

¹³⁴ RR Faden & TL Beauchamp *A History and Theory of Informed Consent* (1986) 252.

¹³⁵ Carstens & Pearmain *Foundational Principles of South African Medical Law* (2007) 878,879.

¹³⁶ SA Strauss, *Doctor, Patient & the Law* 3rd ed (1991) 12.

¹³⁷ *Ibid.*

This might lead to the patient being unable to understand any of the information given and if consent were given, it could not be said to be informed consent.¹³⁸

In summary, it is vitally important that a patient understands, and has a complete appreciation and understanding of the information rendered to him or her by the doctor concerning the proposed treatment or procedure. The patient must also appreciate and understand the consequences that may arise in relation to performing the procedure and if it were not performed. Legislation, case law and health guidelines all endorse the importance of this requirement and have measures in place to ensure that it is carried out. The principle that the patient must appreciate and understand the nature of the harm or risk will be addressed in the context of HIV in Chapter 4.

2.4.2.3 The patient must have consented to the harm or assumed risk

Barring certain exceptions, a doctor has no right to treat a patient unless s/he consents to such treatment.¹³⁹ A doctor who performs a procedure without a patient's consent may be guilty of an assault.¹⁴⁰ However the court in *Broude v McIntosh*¹⁴¹ refused to entertain the appellant's action for damages based on assault and doubted that doctors should be found guilty of assault in such cases.

Marais JA made the following comment:

To the average person and I suspect to many a lawyer, it is a strange notion that the surgical intervention of a medical practitioner whose sole object is to alleviate the pain or discomfort of the patient, and who has explained to the patient what is intended to be done and obtained the patient's consent to it being done, should be pejoratively described and juristically characterized as an assault simply because the practitioner omitted to mention the existence of a risk considered to be material enough to have warranted disclosure and which, if disclosed, might have resulted in the patient withholding consent.¹⁴²

¹³⁸ *Ibid.*

¹³⁹ SA Strauss, *Doctor, Patient & the Law* 3rd ed (1991) 3.

¹⁴⁰ Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 8.

¹⁴¹ *Broude v McIntosh* 1998 (3) SA 60 SCA.

¹⁴² *Broude v McIntosh* supra at 61.

With respect the judge seems to have confused motive with intention because the intention of the doctor was to undertake an operation. The motive of the doctor was to alleviate pain. In any event this was a case of negligence and not assault as there was no intention present.

The question that arises when procuring the patient's consent is whether the consent can be verbal or whether it should be in writing? Consent can be given verbally or in writing.¹⁴³ The Health Professions Council of South Africa in providing guidelines for informed consent have also indicated that although consent can be given orally or in writing, in some cases where the treatment may involve significant risks to the patient, written consent should be obtained from the patient.¹⁴⁴

From the definition set out in *Castell's* case¹⁴⁵ it is important to note that the patient must have legal capacity to give consent, and the treatment which is being consented to must not be against public policy.¹⁴⁶ For example, it would be against public policy for a patient to consent to the amputation of his arm for a reason which is not medically related. Legal capacity involves an enquiry as to whether a person will be competent to enter into the consent process.¹⁴⁷ Dieter Giesen states that consent is valid legally only if it is given freely by a patient with the capacity to consent on the basis that the information which the patient has been given is adequate.¹⁴⁸ What is capacity? Carstens and Pearmain define capacity as referring to the competence of a person which they state is:

The functional ability to meet the demands of specific decision-making situations, weighed in light of its potential consequences.¹⁴⁹

When is a person regarded as being legally capable to consent? A person is capable of consenting to a proposed procedure if s/he is an adult of sound mind and knows what s/he is

¹⁴³ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 70.

¹⁴⁴ Health Professions Council: *Seeking Patients' Informed Consent: The Ethical Considerations* 2nd ed Booklet 10 (2007) Paragraph 13.

¹⁴⁵ *Castell v De Greeff* supra at 425.

¹⁴⁶ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 70.

¹⁴⁷ S Andrews „Informed Consent and HIV“ (2001) 2 (3) *The South African Journal of HIV Medicine* 11.

¹⁴⁸ D Giesen *International Medical Malpractice Law* (1998) 252.

¹⁴⁹ Carstens & Pearmain *op cit* 879.

consenting to.¹⁵⁰ A person is capable of consenting to medical treatment if s/he is over the age of twelve years, sufficiently mature and has the mental capacity to understand the benefits, risks and social implications of treatment.¹⁵¹ A person may consent to a surgical procedure if s/he is over the age of twelve years, sufficiently mature, has the mental capacity to understand the benefits, risks and social implications of the surgical operation and is assisted by his or her parent or guardian.¹⁵²

A patient who is unable to consent due to, for example, mental illness or minority, must be assisted by a parent or guardian or a curator in the case of a mentally ill person.¹⁵³ Van Oosten states that the consenting person should be able to weigh the advantages and disadvantages of the proposed treatment in such a way that after taking into account all of the factors, advantages and disadvantages, s/he will be in a position to make a rational decision as to whether to consent to the treatment or not.¹⁵⁴ Once the patient is able to make a rational decision s/he then has to either consent to the proposed treatment or reject the proposed treatment.¹⁵⁵ In keeping with the principle of autonomy and self-determination, the doctor will have to respect the patient's decision, if the patient were to reject the proposed treatment.¹⁵⁶ The doctor does however have an extended duty of disclosure where the patient refuses treatment. This means that the doctor must explain to the patient the importance of undergoing the treatment or procedure.¹⁵⁷ The doctor must also explain the medical implications of the patient's refusal.¹⁵⁸

Of vital importance is that the consent that is given by the patient must be given freely and voluntarily and without any coercion or duress. Van Oosten states that consent must be free and voluntary, clear and unequivocal, comprehensive and revocable.¹⁵⁹ Any consent obtained

¹⁵⁰ D Giesen *op cit* 318.

¹⁵¹ Children's Act 38 of 2005 s129 (2) (a) & (b).

¹⁵² Section 129 (3) (a), (b) & (c).

¹⁵³ Dada & McQuoid-Mason *op cit* 12,13.

¹⁵⁴ Van Oosten *The Doctrine of Informed Consent in Medical Law* 58.

¹⁵⁵ Steve Andrews „Informed Consent and HIV“ (2001) 2 (3) *The South African Journal of HIV Medicine* 11.

¹⁵⁶ S Andrews *op cit* 12.

¹⁵⁷ Van Oosten, *The Doctrine of Informed Consent in Medical Law* 451,452.

¹⁵⁸ The National Health Act 61 of 2003 s6 (1)(d).

¹⁵⁹ F Van Oosten „The Law and Ethics of Information and Consent in Medical Research“ (2000) 63 (1) *THRHR* 29.

contrary to the above is an invasion of the patient's right to bodily and psychological integrity and is invalid.¹⁶⁰ This right includes the right of a person:

- (a) To make decisions concerning reproduction;
- (b) To security in and control over his or her body;
- (c) Not to be subjected to medical or scientific experiments without his or her informed consent.¹⁶¹

In summary, a patient must provide his or her consent verbally or in writing. The patient must have the legal capacity to consent, i.e. the capacity to understand the implications of his or her consent or refusal. If a patient does not have the capacity to provide consent s/he must be assisted by a competent person. Consent must be given freely and voluntarily without any threat or coercion, and once the patient consents or refuses to consent, the patient's decision must be respected. The principle that the patient must have consented to the harm or assumed risk shall be discussed in the context of HIV in Chapter 4.

2.4.2.4 The consent is comprehensive and extends to the entire transaction, inclusive of its consequences.¹⁶²

The final requirement for informed consent laid down in *Castell's* case¹⁶³ is that the consent given by the patient must be comprehensive and must extend to the entire transaction or treatment including consent to the consequences of such transaction or treatment.

Carstens and Pearmain state that consent must be „clear and unequivocal“¹⁶⁴ In order to achieve this, the doctor is expected to personally discuss the treatment or procedure with the patient and to explain the consequences or complications that may arise.¹⁶⁵ The duty to inform the patient rests on the doctor. It is also suggested that the doctor should make use of a comprehensive consent document.¹⁶⁶ A written consent document, signed by the patient will serve as important

¹⁶⁰ Carstens & Pearmain *op cit* 982.

¹⁶¹ Constitution of the Republic of South Africa Act 108 of 1996 s12 (2) (a)-(c).

¹⁶² Dada & McQuoid-Mason *Introduction to Medical-Legal Practice* 8.

¹⁶³ *Castell v De Greeff* *supra* at 425.

¹⁶⁴ Carstens & Pearmain *Foundational Principles of South African Medical Law* 889.

¹⁶⁵ P Carstens „Informed Consent in South African Medical Law with reference to legislative developments“ Available at <http://new.saml.co.za/node/410> Last accessed on 2012/8/24.

¹⁶⁶ Carstens & Pearmain *Foundational Principles of South African Medical Law* 982.

evidence should the patient later claim negligence by the doctor or a lack of consent.¹⁶⁷ There are of course instances where the doctor may be justified in deviating from the consent provided, but the doctor would have to prove that such deviation was justified. This was illustrated in *Stoffberg v Elliott*¹⁶⁸ where the Plaintiff, a cancer sufferer had sued the doctor following the removal of his penis during exploratory surgery which he had consented to. The Plaintiff's contention was that he had only consented to exploratory surgery and not to the removal of his penis. The doctor's argument was that a deviation from the consent was necessary in order to prolong the life of the plaintiff because he would have died of cancer within two years otherwise.¹⁶⁹ The court found that this was a case of emergency treatment and legally justified. Today however a court would not allow such a deviation and would provide that the patient must be given a choice to decide whether or not to proceed with the surgery.

Strauss has stated that where a patient is undergoing an operation and during the operation another serious condition is detected, the doctor may be justified in deviating from the consent given by the patient to remedy the condition if:

- a) The extension of the operation is in accordance with good medicine;¹⁷⁰
- b) The extension takes place in good faith and in order to alleviate the patient's complaint;¹⁷¹
- c) The risk to the patient is not materially increased;
- d) It would be against the patient's medical interests to first allow the person to recover from anaesthetic in order to give effect to the operation being extended.¹⁷²

In light of the above, it is vitally important that:

- (a) The doctor and patient have a sound relationship based on mutual respect and trust,
- (b) The doctor-patient dialogue is continuous and not one sided,
- (c) The doctor takes cognizance of his patient as an individual,

¹⁶⁷ *Ibid.*

¹⁶⁸ *Stoffberg v Elliott* 1923 CPD 148.

¹⁶⁹ *Ibid.*

¹⁷⁰ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* 75.

¹⁷¹ *Ibid.*

¹⁷² *Ibid.*

- (d) Consent is an ongoing process instead of a single event, recognizing that circumstances may change for the patient.

In summary, this requirement requires that the patient's consent must be comprehensive.¹⁷³ It must encompass the entire transaction and the doctor must explain the consequences and possible complications to the patient. The doctor may only deviate from the consent given in certain specified instances. The consent should ideally be embodied in a written document as it may provide important evidence should the patient later contend that his consent was not informed. The principle that the patient's consent must be comprehensive and must extend to the entire transaction shall be discussed in the context of HIV in Chapter 4.

2.5 Challenges to Informed Consent

As we have seen above the rules of informed consent are crucial to the doctor-patient relationship. Despite this however, there are many challenges with the recognition and implementation of informed consent such as:

- 2.5.1 Informed consent is central to the doctor-patient relationship and if it is neglected or breached it can lead to a breakdown in the relationship with the possibility of litigation. It can also have a negative impact on the doctor's reputation within the community and medical fraternity.¹⁷⁴
- 2.5.2 Although the rules of informed consent have moved from the paternalistic doctor-patient relationship towards one based on patient autonomy, self-determination and share-decision making, there are still doctors who are reluctant to abandon the paternalistic way of practicing medicine and who still advocate the „doctor knows best“ approach.¹⁷⁵
- 2.5.3 In a medical setting such as a hospital one is not always certain who bears the responsibility for obtaining informed consent from the patient. The doctor may

¹⁷³ *Castell v De Greef* supra at 425.

¹⁷⁴ Carstens & Pearmain *Foundational Principles of South African Medical Law* 877.

¹⁷⁵ *Ibid.*

- delegate this responsibility to a nurse. In the event of a subsequent lawsuit for negligence, it might be difficult to apportion blame.¹⁷⁶
- 2.5.4 The application of the doctrine of informed consent through the courts has been viewed as unsatisfactory. The courts have in certain cases been reluctant to find a doctor guilty of negligence and the cause of action in these cases relate to a breach of contract or a breach of a legal duty. It is submitted by Carstens and Pearmain that the action for negligence should rather be based on a breach of the rules of informed consent.¹⁷⁷
- 2.5.5 Many resource constrained countries find the implementation of informed consent rules problematic as they are understaffed and under-resourced, especially in public health facilities. As a result the patient is often not adequately informed and the obtaining of consent becomes academic.¹⁷⁸ Although informed consent should be procedure-specific it usually amounts to a one size fits all approach.¹⁷⁹
- 2.5.6 In the context of HIV, and a culturally diverse country such as South Africa, a doctor may be presented with varying cultural practices of patients which may hinder the process of obtaining informed consent. Patients attending health facilities may hold certain perceptions and superstitions that can negatively impact the doctor-patient relationship and the obtaining of informed consent.¹⁸⁰ For example the myth that if a man has sexual intercourse with a virgin he will not become HIV positive.
- 2.5.7 Often people who are infected are afraid of the stigma and discrimination of HIV and AIDS and may be reluctant to give consent to be tested.¹⁸¹ This challenge will be discussed in Chapter 4.

2.6 Conclusion

The doctrine of informed consent is an integral part of our law. The guiding principles set out in *Castell's* case require that the obtaining of informed consent must be a detailed, informative, on-going process between the doctor and the patient and must be based on mutual trust, respect and

¹⁷⁶ Carstens & Pearmain *Foundational Principles of South African Medical Law* 877.

¹⁷⁷ Carstens & Pearmain *op cit* 878.

¹⁷⁸ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* 82.

¹⁷⁹ Carstens & Pearmain *Foundational op cit* 878.

¹⁸⁰ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* 83.

¹⁸¹ *Ibid.*

consideration. It emphasizes the need to move away from the paternalistic „doctor knows best approach“ towards a patient-centered approach. These requirements have been endorsed in subsequent legislation such as the National Health Act, the Consumer Protection Act and the Constitution. The requirements laid down in Castell’s case will also be discussed in the context of HIV in Chapter 4.

Having examined the sources of South African law which give cognizance to the doctrine, the next chapter examines the ethical aspects of the doctrine of informed consent, and its development in the guidelines of the various medical professional bodies.

CHAPTER 3

ETHICAL ASPECTS OF INFORMED CONSENT

3.1 Introduction

In examining the sources of South African law which deal with the doctrine of informed consent, the provisions of the Constitution and legislation have been discussed in some detail in Chapter 2. The specific provisions of both will, for this reason not be mentioned in this chapter. This chapter will focus on the ethical aspects of informed consent with reference to its development in the medical profession and the ethical guidelines of professional bodies. This discussion must be also seen in the context of its relevance to HIV which will be discussed in Chapter 4. A brief discussion on the legal enforceability of ethical guidelines is also undertaken prior to concluding this chapter.¹⁸²

The role of informed consent in the doctor-patient relationship is an important one as it is a relationship of trust and mutual respect which is established over a period of time. Patients place their lives in the hands of their doctors. Patients trust that doctors will act in their best interests and will make sound medical decisions when taking care of their health. This chapter investigates the origins of the doctor-patient relationship and how over time, instruments and guidelines have been developed to guide those in the medical fraternity through the informed consent process. This chapter also examines the shift from paternalism to self-determination in the doctor-patient relationship. The shift from paternalism to self-determination is reflected in the different ethical codes for the medical profession that have evolved over time since the Hippocratic Oath.¹⁸³

3.2 The Shift from Paternalism to Self-Determination

In the last century we have witnessed a shift from the paternalistic „doctor knows best“ approach to the more inclusive practice of patient autonomy and self-determination. Dieter Giesen describes medical paternalism as a situation where the doctor decides what is best for the patient

¹⁸² See Paragraph 3.6.2.

¹⁸³ See Paragraphs 3.5.1-3.5.3

even though the patient may be competent enough to make their own decision. Paternalists feel that the patient does not possess the knowledge or training that a doctor has and therefore it would be too time consuming and perhaps pointless to attempt to explain the intricacies of complicated medical procedures to the patient.¹⁸⁴

Giesen mentions that there has been a general shift in recent years from paternalism to recognition of the patients' rights to self-determination and autonomy. This school of thinking implies that the patient is competent enough, after being provided with the information from the doctor, to make a decision concerning his or her health. Giesen believes that this right cannot be denied to a person simply because s/he is ill.¹⁸⁵

The submissions made by Giesen echo the rights of the patient as a human being that are entrenched in the South African Bill of Rights as well as the Constitution. Both these emphasize the right of every citizen to privacy, self-determination, autonomy and physical and psychological integrity. Thus there has been a strong move away from a paternalistic approach to consent towards a doctor-patient relationship based on mutual respect, understanding, confidence, trust and loyalty. Should this happen, we will see informed consent take place within a more inclusive patient-centered environment.¹⁸⁶

3.3 The Hippocratic Oath

Historically, the need for consent by patients to medical treatment can be traced back to the time of Hippocrates.¹⁸⁷ Hippocrates, often referred to as „The Father of Medicine“ was a Greek physician who lived around 400BC and who is credited with having formulated the Hippocratic Oath. The Hippocratic Oath is an oath which all doctors entering the profession take and in terms of which they promise to practice their profession in an ethical and noble manner.¹⁸⁸ The Hippocratic tradition centers around two important values which are still pivotal in healthcare

¹⁸⁴ Dieter Giesen „From Paternalism to self-determination to shared decision making“(1988) *Acta Juridica* 107 Available at <http://heinonline.org>. Last accessed on 2013/07/25.

¹⁸⁵ Dieter Giesen *op cit* 116.

¹⁸⁶ Dieter Giesen *op cit* 125.

¹⁸⁷ Carstens & Pearmain *Foundational Principles of South African Medical Law* 875.

¹⁸⁸ Hippocrate's biography Available at <http://www.notablebiographies.com/He-Ho/Hippocrates.html> Last accessed on 2012/12/03.

today. These are that the healthcare practitioner's first duty is to act in the patient's best interest and the second is to avoid harm.¹⁸⁹ These two values became known as the principles of beneficence which means to do good for others and non-maleficence which means to avoid harm or do as little harm as possible.¹⁹⁰ The tenets of the Hippocratic Oath did not mention informed consent and leaned more towards a paternalistic approach to the practice of medicine where the doctor makes decisions that s/he thinks are best for the patient.

As a result of the failure of many to observe the Hippocratic Oath during the Second World War as well as the paternalistic nature of the first oath, a modern version was implemented at the Declaration of Geneva in 1948.¹⁹¹ The Modern Version states that the practitioner will have utmost respect for human life, even under threat and will practice his profession with conscience and dignity.¹⁹² This version of the oath however is paternalistic as it fails to give cognizance to the principles of informed consent, self-determination and autonomy.

3.4 The Nuremberg Trials

During the Second World War there were many heinous human rights contraventions where doctors and scientists ignored the tenets of the Hippocratic tradition and conducted scientific experimentation, castrations and sterilizations on people without their consent. The subsequent Nuremberg trials exposed the fact that the guidelines of the Hippocratic Oath were grossly transgressed. Following the Nuremberg trials, the World Medical Association was established and the Nuremberg Code formulated to determine ethical guidelines for medical practitioners.¹⁹³ The Nuremberg Code specifically states that "The voluntary consent of the human subject is absolutely essential¹⁹⁴ and that „the experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury." The Code also places a duty on all researchers to ensure that the experiment is for the good of society¹⁹⁵ and should at all times

¹⁸⁹ Dhali & McQuoid-Mason *Bioethics, Human Rights & Health Law* 16.

¹⁹⁰ Dhali & McQuoid-Mason *op cit* 14.

¹⁹¹ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* 17.

¹⁹² *Ibid.*

¹⁹³ Dhali & McQuoid-Mason *op cit* 17,18.

¹⁹⁴ Dhali & McQuoid-Mason *op cit* 19.

¹⁹⁵ The Nuremberg Code (1947) s2. Available at

http://www.jewishvirtuallibrary.org/jsource/Holocaust/Nuremberg_Code.html.

avoid unnecessary harm or suffering to the human subject.¹⁹⁶ The subject should also be allowed to opt-out of the experiment.¹⁹⁷ It is evident that the Nuremberg code deals with informed consent by making the voluntary consent of the human subject an absolute essential. Following the atrocities of World War Two and the Nuremberg trials which exposed this, the World Medical Association was formed to provide ethical guidelines for medical practitioners.

3.5 The World Medical Association

The World Medical Association was incorporated in July 1964 as a non-profit educational and scientific organization. The initial idea for its formation began earlier on during World War II when doctors around the world came together to form an organization that would address medical practices in different countries and a uniform code of medical ethics.¹⁹⁸

Some of the guidelines established by the World Medical Association are:

3.5.1 The World Medical Association Declaration of Geneva 1949: International Code on Medical Ethics

This code on medical ethics sets out the ethical duties of medical practitioners in general, to their patients and to their colleagues. It provides that every patient has the right to refuse treatment and that physicians should always act in their patient's best interests, be loyal to patients and respect the patient's right to confidentiality.¹⁹⁹ The code also provides that confidential information can be disclosed when the patient consents to it or when there is a threat of harm to the patient or others. There is no other reference to informed consent.²⁰⁰

3.5.2 The World Medical Association Declaration of Lisbon 1981: The rights of the patient

The Declaration of Lisbon sets out the patient's rights and attempts to recognize the rules of informed consent without specifically referring to them as informed consent rules. It sets out that the patient has the right to self-determination and the right to information which includes the

¹⁹⁶ The Nuremberg Code (1947) s10.

Available at http://www.jewishvirtuallibrary.org/jsource/Holocaust/Nuremberg_Code.html.

¹⁹⁷ The Nuremberg Code (1947) s 9.

Available at http://www.jewishvirtuallibrary.org/jsource/Holocaust/Nuremberg_Code.html.

¹⁹⁸ WMA History. Available at <http://www.wma.net/en/60about/70history/index.html> Last accessed on 2013/07/24.

¹⁹⁹ Dhali & McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 19.

²⁰⁰ WMA International code of medical ethics Available at <http://www.wma.net/en/30publications/10policies/c8/>. Last accessed 2014/07/09.

right to be informed about their health status, treatment options, and the right not to be informed should the patient so choose.²⁰¹ The Declaration also recognizes the patient's rights to dignity and confidentiality.²⁰²

3.5.3 The World Medical Association Declaration of Helsinki 1964: Ethical Principles for Medical Research Involving Human Subjects

The Declaration of Helsinki is a code which provides guidelines for those carrying out research and clinical trials. It is a comprehensive code which specifically provides rules for informed consent in medical research and is mainly concerned with the protection of research subjects during research projects and clinical trials.²⁰³ This is the first code which speaks directly to informed consent.

3.6 Health Professions Council of South Africa

Aside from the international guidelines set out by the World Medical Association (WMA), the Health Professions Council (HPCSA) and the South African Medical Association (SAMA) have also formulated certain codes of conduct and ethical guidelines for those in the medical profession. One of the core values set out by the HPCSA is that practitioners should honour the right of patients to self-determination and to make their own informed choices. This in essence is informed consent and it is evident that the ideal is that the principles of autonomy and self-determination should always be at the centre of the doctor-patient relationship.

It is intended to consider the HPCSA's guidelines on *Seeking patient's informed consent: The ethical considerations*²⁰⁴ The Ethical Guidelines for good practice with regard to HIV will be dealt with in Chapter 4.²⁰⁵

²⁰¹ Dhai & McQuoid-Mason *op cit* 20.

²⁰² Dhai & McQuoid-Mason *op cit* 20.

²⁰³ Dhai & McQuoid-Mason *op cit* 26.

²⁰⁴ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Seeking Patients' Informed Consent: The Ethical Considerations Booklet 9* (2007).

²⁰⁵ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2007).

3.6.1 *Seeking Patients Informed Consent: The Ethical Considerations: Booklet 9.*

The HPCSA booklet on informed consent²⁰⁶ sets out the information that must be given to patients as outlined in the National Health Act 2003. It states that patients must be given information about their health status except when it would be contrary to their best interests.²⁰⁷ It would be contrary to the best interests of the patient in cases where the patient might become so distressed with a poor diagnosis that it would impact negatively on their health. The doctor in such instances may invoke therapeutic privilege in deciding to withhold information in the best interests of the patient.²⁰⁸

The patient must be informed of all of the options available in terms of the procedures and treatments available. The patient must also be advised of the risks, costs and consequences that may arise following each option and the right of refusal. All of this must be communicated to the patient in a language that s/he understands.²⁰⁹

The guidelines which are consistent with the approach in *Castell's* case emphasize that the patient must be informed of all the material risks. A risk is regarded as being material if a „reasonable person“ in the same position as the patient would think it significant. The health care practitioner should also be aware that the patient will attach significance to the facts presented to him.²¹⁰

3.6.2 The legal enforceability of ethical guidelines

The ethical guidelines outlined above provide guidance to medical professionals on the informed consent process. These guidelines are however not legally enforceable unless they co-incide with the provisions of legislation. Upon examination of the guidelines within this chapter and the subsequent chapters it is evident that the ethical guidelines echo the provisions of the National Health Act which sets out the requirements for informed consent.²¹¹ It would follow that a breach

²⁰⁶ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Seeking Patients' Informed Consent: The Ethical Considerations Booklet 9* (2007).

²⁰⁷ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Seeking Patients' Informed Consent: The Ethical Considerations Booklet 9* (2007) Paragraph 3.1.2.1.

²⁰⁸ The National Health Act 61 of 2003 s 6 (1)(a).

²⁰⁹ Section 6 (2).

²¹⁰ *Castell v De Greef* supra at 426.

²¹¹ The National Health Act 61 of 2003 s 6.

of the ethical guidelines by a medical professional will amount to a breach of similar provisions of the National Health Act.

3.7 Conclusion

The history of informed consent and its place in our law can be traced as far back to the time of Hippocrates, the Nuremberg trials and the subsequent guidelines established by the various professional bodies in the health profession. These ethical guidelines and rules are in line with the National Health Act²¹² and the Constitution.²¹³

In this chapter we have witnessed that the historical development of the doctrine of informed consent has been fraught with gross human rights violations such as those in the Second World War where people were subjected to cruel and inhuman treatment.²¹⁴ Over time the rule of law and medical practice has had to evolve to recognize and correct these injustices. The advent and impact of HIV similarly raises controversial issues.

The next chapter focuses on informed consent in the context of HIV and HIV testing. The chapter will focus on how the sources of law provide rules of informed consent in the HIV context with particular reference to pregnant women, their newborn babies and children, the types of testing available, the South African policy approach to HIV testing, and the challenges encountered in testing for HIV.

Bearing these rules in mind, this paper will investigate the exceptions to informed consent. This will be looked at in Chapter 5. Chapter 6 will focus particularly on mandatory testing as an exception to informed consent. The key issue to be discussed is whether there are situations in which the rules set out in the legislation, case law and guidelines by professional bodies can be relaxed to protect individuals from exposure to HIV. The other side of this argument will be whether such a relaxation will amount to an erosion of the rights of the individual being subjected to mandatory testing for HIV. The rights that may be encroached upon are the right to bodily and psychological integrity, the right to self-determination and autonomy, and the right to

²¹² The National Health Act 61 of 2003.

²¹³ The Constitution Act 108 of 1996.

²¹⁴ Dhai & McQuoid-Mason *op cit* 18.

privacy. In examining the various types of HIV testing in chapter 4, is it possible then to propose a middle ground between the two such as that of an opt-out approach to HIV testing?

CHAPTER 4

INFORMED CONSENT IN THE CONTEXT OF HIV AND HIV TESTING

4.1 Introduction

Sources of South African law regarding best practice for HIV provide that no person should be tested for HIV without first obtaining his or her informed consent. Testing a patient's blood without his/her consent may amount to an invasion of his/her right to privacy as well as his/her right to bodily and psychological integrity.²¹⁵

The preceding chapters dealt with the legal and ethical principles of informed consent in South African medical law. However, as the rules of HIV testing are central to this paper, it is imperative to undertake an examination of the legal and ethical rules of informed consent and how they apply to HIV testing in South Africa.

The sources of guidelines for HIV testing have been laid down in the Constitution, legislation, case law, the HPCSA, SAMA guidelines, and policies by government. Informed consent rules underpin these guidelines which will be outlined below.

This chapter also addresses the various types of testing options for HIV as well as the challenges encountered with certain types of testing. Historically voluntary testing and counselling was the first testing option introduced worldwide. However research and literature suggest that this option might not be the best option especially in developing countries where there are many other social and cultural factors to consider. Other options which must be considered are discussed in this chapter.

HIV testing raises informed consent issues for certain high risk or vulnerable groups such as pregnant women and their babies, children, as well as in the case of male circumcisions which has been recently identified as an important preventative measure to reduce HIV transmission.

²¹⁵ Dhai & McQuoid-Mason *Bioethics, Human Rights and Health Law* (2011) 141.

The rules of informed consent as well as testing options available to these groups are also discussed in the latter parts of this chapter.

4.2 Informed Consent

The Constitution and the Bill of Rights together with various statutes protect the rights of citizens to access health care, to access information about their health status and to be informed about decisions affecting their health. Cases which have come before the courts have dealt with instances where these rights have been eroded in the context of HIV. The rights mentioned above and the relevant cases will be discussed below.

4.2.1 The Constitution

The Constitution provides that everyone has a right to have access to health services and the State is obliged to take reasonable legislative steps and other measures within its resources to realize this right.²¹⁶ Health service is defined by the World Health Organisation as any service aimed at contributing to improved health or to the diagnosis, treatment and rehabilitation of sick people.²¹⁷ This implies that the Constitution protects the right of every citizen to have access to health services aimed at the treatment and prevention of HIV and AIDS including testing and treatment of the disease. Government also has a responsibility to ensure that every individual has access to testing and treatment for HIV. The South African National Strategic Plan on HIV, STIs and TB for 2012-2016 has made HIV an imperative and sets goals and strategic objectives which if attained will ensure that HIV is detected, treated and managed.²¹⁸ However translating this responsibility into action has proved challenging for the South African government. These challenges will be discussed further in this chapter. In addition to the right to have access to health services, the Constitution also protects an individual's right to privacy and confidentiality of any medical information. This would include the right not to have the results of an HIV test disclosed to third parties.²¹⁹ This however, is not an absolute right and exceptions will be

²¹⁶ The Constitution Act 108 of 1996 s 27 (a) & (2).

²¹⁷ WHO Health Systems Strengthening Glossary.

Available at: http://www.who.int/healthsystems/hss_glossary/en/index5.html. Last accessed on 2014/06/25.

²¹⁸ South African Department of Health. National Strategic Plan on HIV, STIs and TB 2012-2016 P 2,3.

Available at: http://www.hst.org.za/sites/default/files/hiv_nsp.pdf Last accessed on 2014/09/13.

²¹⁹ The Constitution Act 108 of 1996 s 14 (d).

considered later in this chapter when examining the rights of endangered third parties to have access to such information.

4.2.2 Legislation

The National Health Act provides that every user is entitled to participate in decisions affecting his health and the Act further provides that there is a duty on the health care provider to inform the user of his health status, of any diagnostic procedures and treatment options available to the user.²²⁰ In addition the user must be informed of the benefits, risks and consequences of any intended procedure and his right to refuse together with the implications of such refusal.²²¹ These provisions when applied to HIV testing imply that a person must be fully informed of the testing procedure, risks associated with the test as well as the person's right to refuse to test.

The Promotion of Access to Information Act provides that a requester must be given access to a record of a public body if he/she fulfills the procedural requirements set out in the Act for obtaining access to such record. This request includes a request for access to personal information about the requester.²²² Once a person is tested for HIV he or she is entitled to have access to the test results. These provisions are in line with the Constitution which provide that everyone has the right to access any information held by the state or another person that is required for the exercise or protection of any rights.²²³

4.2.3 Case Law

Cases that have come before the court pertaining to HIV testing focus on the individual's right to privacy, confidentiality as well as the right to provide consent prior to being tested for HIV.

In *C v Minister of Correctional Services*²²⁴ a prison officer tested a prisoner's blood for HIV without obtaining proper consent according to the Department of Correctional Services policy for informed consent. The court found that even though the prisoner had consented to the test, there was no pre-test counselling and hence the test amounted to an invasion of his privacy.

²²⁰ The National Health Act 61 of 2003 s 8(1).

²²¹ Section 6(1).

²²² The Promotion of Access to Information Act 2 of 2000 s 11 (1) (a) & (2).

²²³ The Constitution Act 108 of 1996 s 32(a) & (b).

²²⁴ *C v Minister of Correctional Services* 1996 (4) SA 292 T.

In *Jansen van Vuuren and Another NNO v Kruger*, the court found that disclosure of the plaintiff's HIV status to another medical professional after the plaintiff had expressly requested non-disclosure, amounted to unprofessional conduct and a breach of the plaintiff's right to privacy and confidentiality.²²⁵ The importance of the patient's right to confidentiality was highlighted and the court maintained that the medical practitioner had an ethical and a legal duty to respect the confidence of the patient.²²⁶

In *VRM v Health Professions Council* the appellant appealed against the dismissal of an application in which she alleged that her doctor had acted in an improper and disgraceful manner. She had been his patient during her pregnancy and alleged that an HIV test had been carried out on her without her consent and without her receiving pre-and post-test counselling.²²⁷ The baby was subsequently stillborn and the doctor only informed the appellant at this stage that she was HIV positive. He also informed her that the cause of death of the baby was HIV. The doctor in his defence stated that he had obtained the appellant's consent to the test. He went on to claim therapeutic privilege as a reason for not informing the appellant at an earlier stage of her HIV status and stated that the hospital did not have HIV counselling facilities.²²⁸ The decision of the court was that the matter had not been properly decided as there was a dispute of fact. The court directed that an enquiry be held and did not make any further pronouncements on the matter.²²⁹

In *NM v Smith* the appellants appealed against a judgment in the High Court where they had instituted an action for an infringement of their rights to privacy, dignity and psychological integrity following the publication of their names and HIV status in the biography of Patricia De Lille, without their authority or consent having been obtained. Madala J maintained that a person's HIV status should not be indiscriminately disclosed especially in a South African context where there is the possibility of discrimination and intolerance arising from disclosure. If people were assured of their rights to privacy, it may encourage them to be tested and receive

²²⁵ *Jansen van Vuuren and Another NNO v Kruger* 1993 (4) SA 842 A.

²²⁶ A le Roux-Kemp „HIV/AIDS, to disclose or not to disclose: that is the question“ (2013) 16 1 PER/PELJ 211.

²²⁷ *VRM v Health Professions Council of SA and others* [2003] JOL 11944 (T) at P4.

²²⁸ *VRM v Health Professions Council of SA and others* supra at 6.

²²⁹ *VRM v Health Professions Council of SA and others* supra at 2.

treatment for the disease. The recognition of autonomy and respect for confidentiality may also improve public health policies relating to HIV and AIDS.²³⁰

4.3 Application of the requirements for informed consent to HIV

The requirements for informed consent which were laid down in Castell's case have to be fulfilled within the doctor-patient relationship. These requirements can also be applied to the context of HIV and informed consent that has to be obtained when testing or counselling a patient for HIV. Each of the requirements is dealt with below with specific reference to HIV and HIV testing.

4.3.1 The patient must have knowledge of the nature and extent of the harm or risk

It is important to link this requirement to the obtaining of informed consent when testing a patient for HIV. A person must give informed consent to be tested for HIV and must be provided with pre- and post- test counselling. During counselling the patient must receive information regarding the nature of the disease and depending on whether the results are negative or positive, the patient must be counselled and receive information on the prevention and management of the disease.²³¹

There are exceptions to the rule that the doctor has a duty to disclose the information relating to the proposed procedure or treatment to the patient. These exceptions which will be dealt with in greater detail in Chapter 5 are for example in cases of therapeutic privilege, necessity, where there is a public health risk, or a need for emergency medical treatment.²³²

4.3.2 The patient must appreciate and understand the nature of the harm or risk

Guidelines for HIV testing were set out in *C v Minister of Correctional Services*²³³ where the Department of Correctional Services' policy entitled „Management Strategy: AIDS in Prisons.“ defined and stressed the importance of pre-and post-test counselling in the management of

²³⁰ *NM v Smith* 2007 (5) SA 250 CC at paragraph 42.

²³¹ *C v Minister of Correctional Services* 1996 (4) SA 292 T.

²³² Carstens & Pearmain *op cit* 916, 917.

²³³ *C v Minister of Correctional Services* 1996 (4) SA 292 T.

the disease within correctional services facilities. Specific guidelines for both pre- and post-test counselling were identified as well as the need to have the counselling executed by a trained person.²³⁴

The National Health Act provides that the health care provider must where possible inform the user in a language that s/he understands, taking into account his/her level of literacy.²³⁵ It should imply that where it is not possible for the health care provider to communicate in a language that the user understands, someone else should be consulted to assist in communicating the information to the user. The National HIV Testing and Counselling policy also provides that testing must be voluntary and free of coercion and information must be made available in all official languages, in child friendly versions and in braille.²³⁶

The HPCSA guidelines echo the provisions of the National Health Act in providing that all communication between the health care practitioner and the patient concerning the HIV test should be conducted in a language that is easily understood by the patient and the patient must clearly understand the information given so that s/he can consent to the test based on a proper understanding.²³⁷

4.3.3 The patient must have consented to the harm or assumed risk

The consent that is obtained whether verbal or in writing must be obtained after a proper explanation has been given to the patient by the doctor including an explanation of the patient's right to refuse treatment and the implications of such refusal by the patient.²³⁸ The briefing given to the patient must also be done individually and not in general with other patients as was done in C's case.²³⁹

²³⁴ *C v Minister of Correctional Services* 1996 (4) SA 292 T.

Available at http://www1.chr.up.ac.za/undp/domestic/docs/caselaw_17.pdf Last accessed on 2014/06/08.

²³⁵ The National Health Act 61 of 2003 s 6(2).

²³⁶ South African Department of Health National HIV Counselling & Testing Policy Guidelines March 2010 Paragraph 6.2.

²³⁷ *Ibid.*

²³⁸ Section 6 (1)(d) of the National Health Act.

²³⁹ *C v Minister of Correctional Services* 1996 (4) SA 292 T.

The HPCSA guidelines mentioned above also provide that it is legally and ethically mandatory to obtain a patient's informed consent to an HIV test. The only exceptions cited in the guidelines are in a case of a medical emergency or where a parent or guardian is required to give the necessary consent.²⁴⁰ HIV testing can only take place with the voluntary informed consent of the patient.²⁴¹

The South African Medical Association (SAMA) has also set out guidelines regarding informed consent when testing for HIV. These guidelines provide that any test must be preceded by sufficient information given to the patient to enable him or her to decide whether to consent to the test or not.²⁴² The guidelines further make stipulations for informed consent specifically in relation to HIV testing by stating that:

- a) Consent must be voluntary and without constraint.
- b) Consent should be oral or in writing although written consent is preferable.
- c) Consent must not conflict with the rules of ethics or the Constitution.
- d) The patient must be capable of consenting.
- e) The patient must give the consent personally unless proxy consent is applicable.
- f) The patient should know why the medical practitioner needs the results of the test.
- g) There should be sufficient information about the diagnosis, proposed treatment, expected benefits, risks, alternative treatment, probable results, etc.
- h) The patient must actually understand. If the patient does not understand there must be arrangements for example for an interpreter to assist with procuring understanding.²⁴³

Having regard to the guidelines and requirements set out above this paper will examine the exceptions to the requirement of informed consent and whether there can be any justification to mandatorily test a person's blood for HIV without his or her consent. Will mandatory testing be justified in certain instances or will it amount to a breach of a person's right to

²⁴⁰ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2007) Paragraph 4.3.

²⁴¹ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 12* (2007) Paragraph 6.1.

²⁴² SAMA *Ethical and Human Rights Guidelines on HIV and Aids Part A: General Principles* (2006) Paragraph 3.1.

²⁴³ *Ibid.*

bodily and psychological integrity and an erosion of the patient's right to privacy, autonomy and self-determination? The National HIV Testing and Counselling policy does not support mandatory testing of individuals but recommends voluntary counselling and testing and provider initiated counselling and testing also known as opt-out or routine testing.²⁴⁴ Provider initiated counselling and testing is recommended as a standard component of medical care to all patients attending health care facilities including trauma units and specialist clinics.²⁴⁵ Provider initiated testing must assure that the patient's right to autonomy and dignity are protected whilst placing a corresponding duty on the health care provider to provide access to health services.²⁴⁶

The policy guidelines allow for testing to be done without consent in instances where a sexual offence has been committed provided that a court order is obtained in terms of which the test may be administered by the health care worker. The health care worker must offer the alleged offender pre-test counselling and ensure confidentiality.²⁴⁷ Children who are alleged to have committed a sexual crime may be tested without consent provided that the procedure set out in the Criminal Law (Sexual Offences and Related matters) Amendment Act is complied with.²⁴⁸

4.3.4 The consent is comprehensive and extends to the entire transaction, inclusive of its consequences.²⁴⁹

In applying the above requirement to informed consent for HIV, the Constitution, as we have seen earlier in this chapter, as well as legislation, guidelines and policies all dictate that no person may be subject to testing without his or her informed consent. The HPCSA guidelines further provide that there must be a clear understanding whether or not the patient consents to

²⁴⁴ South African Department of Health National HIV Counselling & Testing Policy Guidelines March 2010 Paragraph 4.2.

²⁴⁵ South African Department of Health National HIV Counselling & Testing Policy Guidelines March 2010 Paragraph 4.2.2

²⁴⁶ *Ibid.*

²⁴⁷ South African Department of Health National HIV Counselling & Testing Policy Guidelines March 2010 Paragraph 8.4

²⁴⁸ South African Department of Health National HIV Counselling & Testing Policy Guidelines March 2010 Paragraph 7.1.

²⁴⁹ Dada & McQuoid-Mason *Introduction to Medical-Legal Practice* 8.

all or only part of the proposed investigation or treatment.²⁵⁰ The Department of Health in its policy guidelines for HIV Counselling and Testing provides that Voluntary Counselling and Testing should be verbal and written. Informed consent for Provider Initiated Counselling and Testing should be verbal and documented in the patient's file by the health care provider.²⁵¹

The nature of the disease and the prejudice and discrimination within which it remains shrouded make it difficult to normalize the disease. People are still reluctant to be tested for fear of stigma and discrimination. Thus HIV testing policies and laws must be sensitive to these difficulties. In this paper it is envisaged that the discussion be taken a step further in examining whether a person can not only be tested for HIV but be tested without his consent and whether there can be a justification for such a test? Will such testing not be seen in the same light as the human rights violations of the Second World War?

4.4 Ethical guidelines for HIV Testing

Ethical guidelines for the implementation of HIV testing and counselling have been laid down by the Health Professions Council of South Africa (HPCSA) as well as the South African Medical Association (SAMA). These guidelines will be outlined below.

Testing for HIV should always be voluntary and carried out only once informed consent has been obtained.²⁵² Informed consent for testing is defined as follows:

In the context of HIV/AIDS testing with informed consent means that the individual has been made aware of, and understands the implications of the test. Consent in this context means the giving of express agreement to HIV Testing in a situation devoid of coercion, in which the individual should feel equally free to grant or withhold consent.²⁵³

²⁵⁰ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 12* (2007) Paragraph 3.1.6.

²⁵¹ South African Department of Health. HIV Counselling and Testing (HCT) Policy Guidelines March 2010 Paragraph 3.2
Available at <http://www.sanac.org.za/.../2-department-of-health-hct-policy-guidelines> Last accessed on 2014/06/02.

²⁵² Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 6.1.

²⁵³ South African Department of Health .HIV/AIDS Policy Guidelines:Testing for HIV, HIV/AIDS and STD (2000) 5. Available at: http://www.hst.org.za/sites/default/files/hiv_nsp.pdf. Last accessed on 2014/09/13.

The only exceptions to this rule are in cases of emergency, where it is authorized by law, court order or there is a threat to public health.²⁵⁴

4.4.1 HPCSA Guidelines

Ethical guidelines for good practice with regard to HIV: Booklet 11

The HPCSA booklet on ethical guidelines for good practice for HIV²⁵⁵ highlights the need to promote the prevention of HIV and to provide access to healthcare. The guidelines set out the ways in which HIV is transmitted²⁵⁶, and the meaning and importance of obtaining informed consent from a patient when seeking to test for HIV²⁵⁷ or to disclose the patient's HIV status to a third party.²⁵⁸ An important element of HIV testing as well as the informed consent process is that of pre- and post-test counselling. Guidelines for HIV testing provide that the person who is about to be tested, must be provided with counselling before the test is carried out. If found to be HIV positive, and the results are given to the person, the person must be provided with post-test counselling as well. During pre-test counselling the person must be given the following information.²⁵⁹

- a) The purpose of the laboratory test;
- b) The advantages or disadvantages testing may hold for him or her as a patient;
- c) Reasons why the health care practitioner wants this information;
- d) The influence that the result of such a test will have on his or her treatment; and
- e) How the patient's medical protocol will be altered by this information.²⁶⁰

The psychosocial impact of a positive test result should also be addressed.²⁶¹

²⁵⁴ SAMA *Ethical and Human Rights Guidelines on HIV and Aids Part A - General Principles* (2006) Paragraph 2.1.

²⁵⁵ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008).

²⁵⁶ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 3.1.

²⁵⁷ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 4.3, 6.5.

²⁵⁸ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 9.

²⁵⁹ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 6.3.

²⁶⁰ *Ibid.*

²⁶¹ *Ibid.*

This information should be discussed in a language that the patient understands.²⁶²

If the test results of the patient reveal that s/he is HIV positive, then it is a requirement of informed consent for HIV testing that the patient must be provided with post-test counselling. In this regard the health care practitioner must ensure that the patient is referred to the appropriate facility to receive such counselling and further care for him/herself, his family and sexual partner.²⁶³

The HPCSA has tailor made the guidelines to take into account the issues surrounding testing for HIV and the importance of ensuring that testing for HIV is an informed consent process.

4.4.2 SAMA Guidelines

Ethical and Human Rights Guidelines on HIV & AIDS

The ethical guidelines for HIV by SAMA have been formulated against the backdrop of the Constitution, HPCSA guidelines and the National Health Act.²⁶⁴

An HIV test can be seen as an invasion of a person's right to privacy and bodily and psychological integrity. Therefore an HIV test can only be administered after obtaining the patient's informed consent.²⁶⁵ The HIV test must always be voluntary²⁶⁶ and must be done with pre-and post-test counselling having been carried out.²⁶⁷ The information laid down by SAMA for during pre-test counselling is the same as that set out by HPCSA with the exception of the following which should also be addressed with the patient:

- a) How long an HIV test takes;

²⁶² Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 6.4.

²⁶³ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 6.6.

²⁶⁴ SAMA *Ethical and Human Rights Guidelines on HIV and AIDS Part A – General Principles* (2006) Paragraph 1.1.

²⁶⁵ SAMA *Ethical and Human Rights Guidelines on HIV and AIDS Part A – General Principles* (2006) Paragraph 2.1.

²⁶⁶ SAMA *Ethical and Human Rights Guidelines on HIV and AIDS Part A – General Principles* (2006) Paragraph 2.2.

²⁶⁷ *C v Minister of Correctional Services* 1996 (4) SA 292 T; cf SAMA *Ethical and Human Rights Guidelines on HIV and AIDS Part A – General Principles* (2006) Paragraph 4.1.

- b) An explanation of the window period and the need for a second test to confirm the results;
- c) The necessity of and coping with lifestyle changes;
- d) Assessment of personal risk of HIV infection;
- e) Coping with a positive result including divulging ones status;
- f) Where support services are and how to access them;²⁶⁸

Post-test counselling takes place after the test results are available and it is the duty of the medical practitioner who requested the test to provide this counselling.²⁶⁹ During post-test counselling where a person tests positive the following should be discussed with the person:

- a) Why it is necessary to disclose the results, to who, when and how;
- b) What health care follow ups are necessary
- c) Available treatments and costs associated with such treatments;
- d) Medical scheme/ health care insurance issues;
- e) Assessing the current situation and planning for the future;
- f) Palliative care and living wills.²⁷⁰

If a person tests negative, post- test counselling should also be offered and should address issues such as:

- g) The window period;
- h) The need to re-test within two months;
- i) Lifestyle changes and how to stay negative.²⁷¹

It is evident that both the HPCSA and SAMA have specific guidelines when testing for HIV. These guidelines also stress the importance of ensuring that testing for HIV is an informed consent process and that the patient is given all the necessary information to enable him or her to

²⁶⁸ SAMA *Ethical and Human Rights Guidelines on HIV and AIDS Part A – General Principles* (2006) Paragraph 4.3.

²⁶⁹ SAMA *Ethical and Human Rights Guidelines on HIV and AIDS Part A – General Principles* (2006) Paragraph 4.4.

²⁷⁰ *Ibid.*

²⁷¹ *Ibid.*

make an informed decision. The guidelines also ensure that the patient receives the medical and psychological support and care needed following a positive result.

4.5 Challenges to HIV Testing

Despite the well formulated rules of law and guidelines pertaining to testing and counselling for HIV, there are many challenges that have been encountered the world over. Some of these relate to implementation, resources and perceptions and are discussed below.

In 1997 the Joint United Nations Programme on HIV/AIDS (UNAIDS) published a technical update called Counselling and HIV/AIDS in which it set out the challenges in providing effective counselling services. Many governmental policy makers, heads of hospitals and non-governmental organisations were sceptical about the value of counselling and questioned its relevance.²⁷² UNAIDS believed that this scepticism and doubt led to several challenges in providing effective counselling services such as :

- a) Lack of approval of policy to begin counselling services;
- b) Lack of space and resources for counselors;
- c) Intimidating or inappropriate counselling atmosphere in clinics; and
- d) Lack of privacy and confidentiality.²⁷³

The update further set out the success stories in countries such as Uganda and Rwanda where counselling had proved effective in helping HIV positive persons cope with the knowledge of their status and the disease. It also helped people within the community and family members to be more supporting and accepting of those diagnosed as HIV positive.²⁷⁴

In an effort to help alleviate the challenges, UNAIDS suggested certain interventions such as:

- a) Conducting of research studies to convince key role-players on the importance of counselling;
- b) Proper selection of trainees for counselling;
- c) Supervision of trainees after workshops have taken place;
- d) Retention of trained counselors; and

²⁷² UNAIDS Technical update .Counselling and HIV/AIDS. November 1997 P2.

²⁷³ *Ibid.*

²⁷⁴ UNAIDS Technical Update. Counselling and HIV/AIDS. November 1997 P3.

e) Good referral systems.²⁷⁵

Whilst advances in treatment and counselling were made in the West and the initial hysteria regarding the spread of the disease subsided to a certain extent, the situation in Africa presented a different picture.²⁷⁶ As at the end of 1998 there were 33,4 million people living with HIV worldwide of whom 22,5 million were in sub-Saharan Africa. AIDS thus became the leading cause of death in Africa.²⁷⁷ The World Health Organisation responded with the Special Programme on AIDS. Yet, despite the alarm bells, many African countries still did not regard HIV as a priority.²⁷⁸ Funding and resources to respond to the epidemic was also limited and the disease was still seen as a phenomenon of the West.

In 1999 UNAIDS published data about the global spread of the diseases including sub-Saharan Africa. The report set out that in 1998, sixteen thousand individuals were infected with HIV daily. By the end of that year over thirty three million people were living with HIV and it is estimated that nine tenths of whom were unaware of their HIV status.²⁷⁹ The report went on to emphasize the value of voluntary HIV counselling and testing citing research into the benefits of reducing risky behavior as an impetus to implement wide scale testing and counselling.²⁸⁰

Initially treated with caution, HIV testing and counselling came to be viewed as beneficial once the benefits of reducing mother to child transmission became evident. The view emerged that HIV testing and counselling could not be treated as „exceptional“ and that testing and counselling should be available in health care settings.²⁸¹

²⁷⁵ UNAIDS Technical Update. Counselling and HIV/AIDS. November 1997 P7.

²⁷⁶ UNAIDS Technical Update. Counselling and HIV/AIDS. November 1997 P13.

²⁷⁷ *Ibid.*

²⁷⁸ KM De Cock, D Mbori-Ngacha & E Marum „Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century“ (2002) 360 *The Lancet* 68.

²⁷⁹ The UNAIDS Report 1999 P7. Available at http://www.data.unaids.org/publications/IRC-pub01/jc208-corpreport_en.pdf Last accessed on 2014/09/13.

²⁸⁰ The UNAIDS Report 1999 P37.

²⁸¹ R Baggeley, B Hensen, O Ajose, KL Grabbe, VJ Wong, A Schilsky, Y-R Lo, F Lule, R Granich & J Hargreaves „From caution to urgency: the evolution of HIV testing and counselling in Africa“ (2012) 90 *Bulletin World Health Organisation* 652.

In 2003 the World Health Organization declared a global health emergency when it was discovered that only one percent of those in need of anti-retroviral treatment were indeed able to access such treatment. Fewer than ten percent of infected persons were aware of their status.²⁸²

Despite the availability of voluntary counselling and testing, very few people were accessing testing and as a result did not know their status and did not access treatment. Pre- and post-test counselling efforts were also seen as fostering exceptionalism and as such placing a strain on resources and time. The opt-in approach to testing required in depth counselling, was time consuming and resource-draining. People were also afraid of being stigmatized and therefore did not access testing voluntarily.²⁸³ Further, the medical practitioner would only test a patient for HIV if he or she exhibited symptoms that suggested the presence of HIV, TB or a sexually transmitted disease.²⁸⁴

These stark statistics motivated initiatives and support towards increasing access to treatment and exploring other testing options. Voluntary counselling and testing came to be seen as insufficient with a need to examine and implement alternative approaches. As a result of this change in thinking, the option of opt-out testing emerged.²⁸⁵

4.5.1 Opt-out testing (also known as Provider Initiated HIV Testing and Counselling/Routine Testing)

In 2007 the World Health Organisation released guidelines in which it recommended the implementation of opt-out testing in settings with high HIV prevalence to all adults accessing health care facilities.²⁸⁶ During opt-out testing the patient is offered HIV testing at the health care centre where s/he presents himself/herself regardless of the medical reason for their visit to the health care centre.²⁸⁷ The test is carried out after informing the person that it will be done and consent is inferred unless the patient declines the test.²⁸⁸

²⁸² *Ibid.*

²⁸³ D McQuoid-Mason „Routine testing for HIV – ethical and legal implications“ (2007) 97 (6) *SAMJ* 416.

²⁸⁴ T Metz „The ethics of routine HIV Testing: A respect based analysis“ (2005) *SAJHR* 374.

²⁸⁵ *Ibid.*

²⁸⁶ MD April „Rethinking HIV exceptionalism: the ethics of opt-out HIV testing in Sub-Saharan Africa“ (2010) 88 *Bulletin of the World Health Organisation* 703.

²⁸⁷ P Cherutich, R Bunnell and J Mermin „HIV Testing: Current Practice and Future Directions“ (2013) 10 *Curr HIV/AIDS Rep* 136.

²⁸⁸ K Moodley *Medical Ethics, Law and Human Rights A South African Perspective* (2011) 15.

Opt-out testing was first introduced in Botswana in 2004, in Uganda in 2005 and in South Africa in 2007. The goals set by the South African government in its Strategic Plan for HIV and AIDS and STIs 2007-2011 were to reduce new HIV infections by 50% and to provide access to treatment to 80% of already infected persons by 2011.²⁸⁹ In order to achieve this government made uptake of voluntary counselling and testing an imperative. Testing allows people to become aware of their status and to enable them to make changes in their behaviour to reduce transmission.

Advantages of Opt -out testing

The availability of treatment should be a pre-condition for opt-out testing as it is pointless to test a patient without being able to provide him or her with treatment. This is especially true in low income and resource-deficient countries.²⁹⁰

Some of the advantages of opt-out testing are:

- a) If individuals are tested early, this would mean that treatment can be implemented sooner and the chances of survival, greater. This would imply a decrease in mortality rates as well.²⁹¹
- b) Administering opt-out testing to pregnant mothers will mean that more infants will have access to treatment earlier, therefore increasing the survival rate of such children.²⁹²
- c) Advantages in testing technology make expanded testing easier as patients can be tested with rapid tests and receive their results immediately in a single visit.²⁹³
- d) Rapid tests which make use of oral samples will alleviate the need to prick the patient's finger and may thus reduce the risk of infection through needle stick injuries.²⁹⁴
- e) The time required to test each patient will be less for opt-out testing than for opt-in testing since extensive counselling and specific consent is not needed. This will make it possible to test a greater number of patients.²⁹⁵

²⁸⁹ South Africa Department of Health. Strategic Plan for HIV and AIDS and STIs 2007-2011. P10. Available at <http://www.tac.org.za/documents/NSP-Draft10-2007-2011.pdf>. Last accessed on 2014/09/13.

²⁹⁰ MD April *op cit* 704.

²⁹¹ MD April *op cit* 703,704.

²⁹² MD April *op cit* 704.

²⁹³ M Hamill „Time to move towards opt out testing for HIV in the UK“ (2007) 334 *BMJ* 1352.

²⁹⁴ *Ibid.*

- f) It is believed that opt-out testing would eliminate exceptionalism and HIV would be treated as any other disease.²⁹⁶
- g) Even if anti-retroviral therapy was not available, it would still be beneficial for a person to know his or her status and modify his or her behavior. This would lead to a reduction in the number of infections as partners and spouses could be informed.²⁹⁷

Disadvantages of Opt-out testing.

Some of the disadvantages of opt-out testing are:

- a) Poorer countries may not have enough resources to meet the treatment needs of all those who are tested and found to be positive.²⁹⁸
- b) Individuals who are tested and found to be positive might experience discrimination, stigma, and job loss, physical and verbal abuse.²⁹⁹
- c) It is questionable whether opt-out testing cannot be seen as a breach of a patient's right to autonomy. Is it justifiable to test a patient arguing that it is in his or her best interests to do so? If we give patients the opportunity to refuse to test, does this mean that it is a test that is free of coercion and paternalistic practices?³⁰⁰
- d) The disadvantage of opt-out testing is that people are only tested when they attend a health care facility. If they did not attend a hospital and clinic they would not be tested and would not know their status. As a result, there were suggestions that home based or community testing be implemented in addition to provider initiated testing and counselling.
- e) Pre-test counselling and stringent informed consent requirements may enhance stigma and discrimination.³⁰¹

²⁹⁵ M Hamill *op cit* 1353.

²⁹⁶ C Van Wyk. The Legal Aspects of HIV/AIDS. Presentation delivered at an academic seminar during the Unisa inspired week in the ZK Matthews Hall on 21st June 2006 P86.

²⁹⁷ T Metz *op cit* 397.

²⁹⁸ MD April *op cit* 704.

²⁹⁹ *Ibid.*

³⁰⁰ MD April *op cit* 705.

³⁰¹ C Van Wyk *op cit* 86.

- f) Patients may be afraid to refuse a test that is being offered by a person that they trust and respect. They may also fear that their treatment may be compromised if they refuse to be tested for HIV.³⁰²

4.5.2 Other types of testing

In view of the challenges faced with the low uptake of voluntary counselling and testing and despite the introduction of opt-out testing, there are many who are still unaware of their HIV status³⁰³ This implies that other testing strategies should be considered for implementation in order to present people with various options for testing. It is imperative however that any type of testing should adhere to the requirements of informed consent and should be non-coercive. The two types of testing which will be discussed below are mobile voluntary counselling and testing and self- testing. Although this paper focuses on informed consent and mandatory testing, these types of testing are discussed to establish a background to the types of testing options available. These are also alternatives to VCT and opt-out testing and may help to increase the number of those who are tested and treated for HIV. An examination of self-testing has also been included in this chapter as it is discussed as part of the recommendations in the concluding Chapter 7.

The rules of informed consent are discussed in relation to these types of testing and it is submitted that both mobile testing and self-testing meet the requirements for informed consent and voluntary counselling and testing. Mandatory testing for HIV does not meet the requirements of voluntary counselling and testing. Mandatory testing forms the focus of Chapter 6 where it will be discussed in detail.

a) Mobile Voluntary Counselling and Testing

In a South African study conducted in 2012 it was found that more women than men and youth access voluntary counselling and testing facilities. As a result many men and youth are unaware

³⁰² *Ibid.*

³⁰³ H van Rooyen, N McGrath, A Chirwodza, P Joseph, A Fiamma, G Gray, L Richter and T Coates „Mobile VCT: Reaching Men and Young People in Urban and Rural South African Pilot Studies (NIMH Project Accept, HPTN 043)“ (2013) 17(9) *Aids and Behaviour* 2946.

of their HIV status.³⁰⁴ Some of the barriers which prevented these groups from accessing testing in public health facilities were inconvenience of clinic hours and attitude of staff³⁰⁵ Issues of privacy and confidentiality were also cited as barriers to testing³⁰⁶ In order to alleviate this challenge one of the options proposed in the study was mobile testing and counselling. Mobile voluntary counselling and testing involves the provision of counselling and testing services through tents and caravans or other temporary accommodation at convenient locations in the community.

Benefits of Mobile Testing

The results of this study showed that mobile testing and counselling sites which were conveniently located within the community attracted more men and youth to test and recommended the scaling up of testing and treatment via alternate methods or systems. The fact that people do not have to travel to clinics thereby incurring costs and spending more time at sometimes inconvenient locations makes mobile testing a popular and convenient option for all.³⁰⁷ Mobile testing also implies that people do not have to attend a health facility to be tested. Hence testing can be extended to more individuals and not just to the ill or to pregnant women.³⁰⁸ Participants of mobile voluntary counselling and testing are provided with pre- and post-test counselling which ensure that even though the test is not administered in a health care facility, the rules of informed consent are observed in order to ensure that testing is informed and voluntary.

Concerns about Mobile Testing

Mobile testing sites may be more visible in a community thereby failing to provide the anonymity and privacy that individuals need. People may be afraid to attend the mobile testing site for fear that they may be perceived by others as being HIV positive.³⁰⁹

³⁰⁴ H van Rooyen, N McGrath, A Chirowodza, P Joseph, A Fiamma, G Gray, L Richter and T Coates „Mobile VCT: Reaching Men and Young People in Urban and Rural South African Pilot Studies (NIMH Project Accept, HPTN 043)“ (2013) 17(9) *Aids and Behaviour* 2947.

³⁰⁵ H van Rooyen *op cit* 2497.

³⁰⁶ H van Rooyen *op cit* 2951.

³⁰⁷ H Van Rooyen, L Richter, TJ Coates & M Boettiger „Approaches to HIV Counselling and Testing: Strengths and Weaknesses, and Challenges for the Way Forward“ in P Rohleder (ed) *HIV/AIDS in South Africa 25 years on. Psychosocial Perspectives* (2009) 173, 174.

³⁰⁸ H Van Rooyen, L Richter, TJ Coates & M Boettiger *op cit* 174.

³⁰⁹ *Ibid.*

b) Self –Testing

HIV self-testing occurs where a person is able to determine his HIV status through the collection of a specimen from his body with which he or she performs the test.³¹⁰ A self-testing kit can be purchased over the counter at pharmacies and enables the user to take the test using an oral swab of saliva. The person is able to determine the results within a few minutes in private and without the need to take a blood sample. This test can be taken in the privacy of the home without the involvement of a third party.³¹¹ The person taking the test is offered pre-and post-test counselling in the form of a pamphlet or through telephonic contact with a counselor. The counselor can provide counselling and referrals to the individual in the event that he or she tests positive.³¹² It is submitted that this is sufficient for the requirement of voluntary counselling and testing and meets the standards of informed consent.

There are various approaches to and models for testing such as supervised self-testing, non-supervised self-testing and community based self-testing. The type of model used would depend on the needs of the target group or community. Self-testing and a discussion of the various models will be addressed further in the concluding chapter of this paper when making recommendations for the future.

Benefits of self-testing

The benefits of self-testing are:

- a) Earlier access to testing;
- b) Earlier diagnosis for people who may not be able to access a health care facility;
- c) Convenience and privacy when administering the test, thereby eliminating the fear of stigma and discrimination;

³¹⁰ World Health Organisation. HIV Self –Testing. Supplementary section to the 2013 WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, Chapter 5 – HIV diagnosis and ARV drugs for HIV prevention P12. Available at http://apps.who.int/iris/bitstream/10665/104264/1/978924156830_eng.pdf?ua=1
Last accessed on 2014/08/27.

³¹¹ AE Storde, H Van Rooyen & T Makusha „Is it lawful to offer HIV self-testing to children in South Africa? (2013) 14.(4) *SAJHIVMED* 151.

³¹² J Gardner „HIV Home Testing-a problem or part of the solution?“ (2012) 5(1) *SAJBL* 15

- d) It may serve as greater testing opportunities for vulnerable groups such as men who have sex with men, sex workers, health workers etc. This might lead to a reduction in risky behavior and more people being tested; and
- e) It may serve to complement existing public health testing facilities and reduce the risk of exposure to HIV.³¹³
- f) Once a person purchases a test, this indicates his willingness to test and informed consent concerns are minimized. Pre- and post-test counselling information is available in printed form or through telephonic contact with a counselor.³¹⁴

Concerns about Self-testing

Some of the concerns expressed with this type of testing are that there is no face to face counselling and taking the test in private may further enhance stigma and the shrouding of the disease in secrecy.³¹⁵ Self-testing is a screening process only and does not provide a conclusive diagnosis. The person would still have to undergo further testing to achieve a definitive diagnosis.³¹⁶ As self-testing is a fairly new testing option, many countries are still to develop policy around the regulation of such testing. South African testing policy does not currently make provision for self-testing but it is an option that is being considered for policy development.³¹⁷

³¹³ World Health Organisation. HIV Self –Testing. Supplementary section to the 2013 WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, Chapter 5 – HIV diagnosis and ARV drugs for HIV prevention. P15. Available at http://apps.who.int/iris/bitstream/10665/104264/1/978924156830_eng.pdf?ua=1
Last accessed on 2014/08/27.

³¹⁴ J Gardnder *op cit* 16..

³¹⁵ AC Van Dyk „Self-testing as strategy to increase the uptake of HIV testing in South Africa“ (2013) 12(1) *African Journal of Aids Research* 42.

³¹⁶ World Health Organisation. HIV Self –Testing. Supplementary section to the 2013 WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, Chapter 5 – HIV diagnosis and ARV drugs for HIV prevention. P12. Available at http://apps.who.int/iris/bitstream/10665/104264/1/978924156830_eng.pdf?ua=1
Last accessed on 2014/08/27.

³¹⁷ World Health Organisation. HIV Self –Testing. Supplementary section to the 2013 WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, Chapter 5 – HIV diagnosis and ARV drugs for HIV prevention. P13. Available at http://apps.who.int/iris/bitstream/10665/104264/1/978924156830_eng.pdf?ua=1
Last accessed on 2014/08/2.

There have been other concerns relating to the use of the test by untrained persons and the possibility of flawed results or testing during the window period.

4.6 HIV Counselling and Testing of Pregnant Women

Pregnant women have been identified as a „vulnerable group“ within the context of HIV. This is more so in South Africa and the following statistics indicate the urgency and need to prioritize the needs of pregnant women and their babies. There is general consensus among those in the field of HIV that Voluntary Counselling and Testing for pregnant women does not work. Some of the hurdles to testing are fear of stigma and discrimination, fear of abuse and violence from partners. Many women who do test do not return to be informed of their results.³¹⁸ The question that arises then is which testing option would best be implemented for pregnant women? Should testing remain voluntary despite failure indicators or should testing be solely opt-out, or even mandatory?

In 2010 30,2% of all pregnant women who attended public health care facilities were infected with HIV and in 2011 an estimated 70,4 % of maternal deaths were associated with HIV infection. Half of the deaths of children under the age of 5 years could also be attributed to HIV infection.³¹⁹

In light of these staggering statistics, HIV testing and treatment is critical for both pregnant women and their babies. A combination of anti-retroviral therapy, elective caesarean section delivery and utilizing formula feeding was thought to reduce the risk of mother to child transmission.³²⁰ However there has been much debate about whether breastfeeding carries an increased risk of HIV transmission from mother to child and whether a mother should breastfeed her newborn or use alternative feeding options. The current World Health Organisation, UNAIDS and United Nations Childrens“ Fund (UNICEF) guidelines recommend that mothers breastfeed their babies if replacement feeding is not available or if it is not safe, affordable,

³¹⁸ PA Clark „Mother- to- Child Transmission of HIV in Botswana: An Ethical Perspective on Mandatory Testing“ (2006) 6(1) *Developing World Bioethics* 7.

³¹⁹ P Barron, Y Pillay, T Doherty, G Sherman, D Jackson, S Bhardwaj, P Robinson & A Goga „Eliminating mother-to-child HIV transmission in South Africa“ *Bulletin of the World Health Organisation* 1.

³²⁰ S Walmsley „Opt in or opt out: What is optimal for prenatal screening for HIV infection?“ (2003) 168(6) *CMAJ* 707.

sustainable or affordable.³²¹ New infections however continue to occur in countries where pregnant women do not have access to testing and treatment options.³²²

In 1998 the health minister announced that the drug called Zidovudine would not be made available to pregnant women in South Africa. The reason given for this was that the cost to test and treat pregnant women was too high. This was one of the first battles between government and civil society. AIDS activists, researchers and church leaders protested against this decision by the health minister.³²³

In 2001 the Treatment Action Campaign (TAC) and others brought an application in the High Court against government. The basis of their application was that government be ordered to give everyone access to public health services and that the right of children be given special attention.³²⁴ They had also asked that government be obliged in terms of the Constitution, to plan and implement an effective programme to prevent mother to child transmission of HIV countrywide.³²⁵ The government had a policy in place to provide nevirapine only at certain pilot sites in South Africa despite the fact that the drug was offered free of charge by the manufacturer for a period of five years.

The High Court decided that the government was obliged to provide Nevirapine to pregnant HIV positive women who gave birth in the public sector and to their babies. Such women had to be properly counselled and tested.³²⁶ Government was also ordered to implement a comprehensive national programme to prevent or reduce mother to child transmission of HIV and to provide voluntary counselling and testing, Nevirapine and formula milk for feeding of the baby. Government appealed the decision of the High Court. The concerns by government related to the costs necessary to provide voluntary counselling and testing and to provide formula and other

³²¹ WHO/UNAIDS/UNICEF infant feeding guidelines. Available at <http://www.unicef.org/programme/breastfeeding/feeding.htm>. Last accessed on 2014/08/07.

³²² *Ibid.*

³²³ N Natrass *op cit* 47.

³²⁴ *Minister of Health & Others v Treatment Action Campaign & Others* (No 2) (CCT8/02) [2002] paragraph 4.

³²⁵ *Minister of Health & Others v Treatment Action Campaign & Others* (No 2) (CCT8/02) [2002] *supra* at paragraph 5.

³²⁶ *Minister of Health & Others v Treatment Action Campaign & Others* (No 2) (CCT8/02) [2002] *supra* at paragraph 8.

antibiotics and vitamins.³²⁷ Providing Nevirapine to the pregnant mother would be almost useless if the child still became infected through drinking of breast milk following birth. Recent studies however have caused the World Health Organisation to issue new guidelines regarding the risk of infection through breastfeeding which indicate that a combination of exclusive breastfeeding and the use of antiretroviral treatment can significantly reduce the risk of transmitting HIV to babies through breastfeeding.³²⁸

In the TAC case, the court in setting aside the judgment of the High Court declared that Section 27(1) and (2) of the Constitution required government to implement within its available resources a comprehensive plan to realise the rights of pregnant women and their babies to access health services to combat mother to child transmission of HIV.³²⁹ The judgment in this case was a landmark one in that it forced government to confront its constitutional obligations to provide access to health care to pregnant mothers and to make counselling and testing central to the process.

Prevention of Mother to Child Transmission programmes (PMTCT) were finally implemented in 2002. Although PMTCT has become routine and universal other challenges have emerged such as the need to know whether pregnant mothers continue their treatment once tested positive, whether infants are tested and treated following birth? How does one follow up and implement treatment after testing?³³⁰

One of the questions to be answered is which testing option is best suited to pregnant women? Should pregnant women be offered opt- in testing or opt- out testing? Should mandatory testing of pregnant women be considered especially in countries where the infection rate is extremely high or will this type of testing be an invasion of the privacy of the pregnant woman?

³²⁷ *Minister of Health & Others v Treatment Action Campaign & Others* (No 2) (CCT8/02) supra at paragraph 49.

³²⁸ L Langa „Breast is always Best even for HIV positive mothers” (2010) 88 *Bulletin of the World Health Organisation* 10. Available at <http://www.who.int/bulletin/volumes/88/1/10-030110.pdf>. Last accessed 2014/07/07.

³²⁹ *Minister of Health & Others v Treatment Action Campaign & Others* (No 2) (CCT8/02) supra at paragraph 135.

³³⁰ P Barron et al *op cit* 2.

Advocates for mandatory testing believe that the benefits to the mother and child in knowing their status and commencing treatment justify any invasion of the mother's right to privacy or fears that the mother may forego counselling. It is argued that mandatory testing is necessary for the preservation of life as well as the care afforded to both mother and infant.³³¹ Another argument proffered in favour of mandatory testing is the fact that voluntary counselling and testing has not shown much success. Women are afraid of being stigmatized and suffering abuse from their partners so many do not attend VCT sites or when they do, they do not return for their results.³³² Some of the concerns raised about the implementation of a mandatory testing policy for pregnant women are whether mandatory testing may lead to women failing to access pre-natal care and an erosion of the trust in the doctor-patient relationship.³³³ A further concern is how a court would implement anti-retroviral treatment during the period of confinement and thereafter?³³⁴

In light of the above it seems that mandatory testing of pregnant women presents an extremely invasive approach and would be difficult to implement and follow through with. Due to the long period of confinement it would also represent a huge and unsustainable cost burden to the state especially in resource-constrained countries.³³⁵

Certain provinces in Canada adopted the opt-out approach to testing as early as 1998 and found that a very small percentage of women (4,7%) refused testing. It was also found that the rate of HIV testing in pregnancy increased from 75% to 88%.³³⁶ Caution has however been expressed about the negative implications of not obtaining traditional informed consent, also citing discrimination, rejection and partner violence as possible outcomes of a positive result. It is imperative that the patient receive proper counselling on these possibilities and how to manage them. Partners should also receive counselling and be given the option to test as well.³³⁷

³³¹ PA Clark *op cit* 3.

³³² PA Clark *op cit* 7.

³³³ DL Eden „Is it Constitutional and will it be effective? An analysis of Mandatory HIV testing of Pregnant Women“ (2001) *II Health Matrix* 682.

³³⁴ DL Eden *op cit* 684.

³³⁵ *Ibid.*

³³⁶ S Walmsley *op cit* 708.

³³⁷ S Walmsley *op cit* 707.

The United States currently offers opt-out testing to pregnant women who present for ante-natal care but not to the general medical population.³³⁸

It would seem that opt-out testing presents a somewhat middle ground between voluntary testing and counselling and mandatory testing. It may seem more feasible to offer opt-out testing at public health facilities and to increase efforts to reduce the fear stigma, discrimination and partner abuse attached to a positive diagnosis. Some of the suggestions to reduce these are the provision of legal services and materials in health clinics,³³⁹ as well as introducing couple testing instead of mother only testing.³⁴⁰ Couple testing may reduce the often incorrectly held perception of „first tested, first infected“ and may promote the view that response to HIV should be a family response which involves the mother, father and children and not just the mother and child.³⁴¹

4.7 HIV Counselling and Testing of Children

In 2010 it was estimated that 3,4 million children below the age of 15 years were HIV positive worldwide. 90% of these children were living in sub-Saharan Africa. In 2011 UNAIDS estimated that in South Africa there were about 460 000 children younger than 14 years of age who were living with HIV.³⁴² Aside from being infected with HIV, children are also severely affected by HIV and AIDS. Many children in South Africa have been orphaned following the death of their parents or caregivers from HIV and AIDS. As a result many such children have to take care of themselves and live in child-headed households. Who is responsible for providing informed consent when a child below the age of 12 years and living in a child-headed household has to have an HIV test or receive treatment for HIV?³⁴³

Section 28 of the Constitution protects the rights of all children and these rights are echoed in the provisions the Children's Act 38 of 2005. Every child has the right to have access to information on health promotion and the prevention and treatment of ill health and disease, to have access to

³³⁸ T Metz *op cit* 373.

³³⁹ P Rohleder, L Swartz, SC Kalichman, LC Simbayi (eds) *HIV/AIDS in South Africa 25 years on. Psychosocial Perspectives* (2009) 194.

³⁴⁰ P Rohleder et al *op cit* 192.

³⁴¹ *Ibid.*

³⁴² AE Strode „Is it lawful to offer HIV self-testing to children in South Africa“ (2013) 14(4) *SAJHIVMED* 151.

³⁴³ Carstens & Pearmain *op cit* 115.

information regarding his or her health status and to confidentiality of information relating to his or her health status.³⁴⁴

No child may be tested for HIV except when it is in his or her best interests and when consent has been given.³⁴⁵ A child may consent to an HIV test if he or she is 12 years or older.³⁴⁶ The HIV test may only be administered once the child has received pre-test counselling from a trained counsellor.³⁴⁷

A child under the age of 12 years may consent to an HIV test if he or she is of sufficient maturity to understand the benefits, risks and implications of the test and the test is in his best interest.³⁴⁸ If a child is not sufficiently mature to understand the benefits, risks and implications of the test then the parent or care-giver of the child may consent to the test.³⁴⁹ The difficulty that may arise is when a child under the age of 12 years, who is not sufficiently mature and lives in a child-headed household needs to take an HIV test. Who will provide the necessary consent if the child does not have a guardian or care-giver? In South Africa, as outlined earlier, there are many AIDS orphans who are forced to take care of themselves and other siblings and who will present a dilemma to health care workers when seeking an HIV test.

Pre- and post- test counselling must also be given to the child by a trained counsellor and the test must be in the best interests of the child.³⁵⁰ Where a child below the age of 12 years is orphaned, the Children's Act makes provision for consent to an HIV test to be given by a designated child protection organization or the superintendent or person in charge of a hospital.³⁵¹

³⁴⁴ The Children's Act 38 of 2005 s 13(1) (a), (b) & (d).

³⁴⁵ Section 130(1).

³⁴⁶ Section 130(2) (i).

³⁴⁷ Section 132(1) (a) & (b).

³⁴⁸ Section 130(2) (a) (ii).

³⁴⁹ Section 132(2) (b).

³⁵⁰ Section 132(2) & 130 (1) (a).

³⁵¹ Section 130 (2) (d) & (e).

A court may also authorize HIV testing of a child where the test is necessary to establish whether a health care worker or any other person may have become infected through exposure with any substance from the child's body during a medical procedure which may cause HIV.³⁵²

If a parent or caregiver is incapable or unreasonably withholds consent for an HIV test to be administered on a child, then the children's court is empowered to provide consent.³⁵³ What is the position where a child over the age of 12 years refuses to consent to an HIV test when it is in his best interests to have the test? A child over the age of 12 years has the right to refuse to undergo an HIV test, but if his or her refusal is „unreasonable“ then the Minister of Social Development may consent on his or her behalf. If a parent or caregiver of the child's refusal is unreasonable then he or she may apply to the High Court for an order to have the child take the HIV test.³⁵⁴

The Ugandan National Policy guidelines for HIV also provide that children over the age of 12 years may consent to an HIV test without parent or guardian consent. The child must however be able to understand the implications of the test results. Children below the age of 12 must be assisted by their parents. Despite these guidelines, Ugandan health workers have experienced many challenges in providing testing services to children.³⁵⁵ Some of these challenges which are outlined below may be common to South Africa where there are many AIDS orphans:

- a) Children find it difficult to express themselves and need more counselling. Some children are sent to hospital alone and become attached to the healthcare worker who provides testing services to the child.³⁵⁶
- b) Some health care workers are not trained to handle children. Some children have witnessed their parents dying from AIDS and fear death. Some children refuse to take treatment.

³⁵²Section 130 (1) (b) (i).

³⁵³Section 130 (2) (f) (i) & (ii).

³⁵⁴DJ McQuoid-Mason „Can children aged 12 years or more refuse life-saving treatment without consent or assistance from anyone else?“ (2014) 104(7) *SAMJ* 467.

³⁵⁵J Rujumba, CL Mbasaalaki-Mwaka & G Ndeezi „Challenges faced by health workers in providing counselling services to HIV- positive children in Uganda: a descriptive study“ (2010) 13 (9) *Journal of the International Aids Society* 2.

³⁵⁶J Rujumba et al *op cit* 4.

- c) Fear of stigma and discrimination sometimes means that caregivers do not allow children to be tested or remove them from school in the belief that there is no point educating a child who is going to die.
- d) Other challenges related to the lack of proper paediatric knowledge on the part of healthcare workers, lack of counselling and resource constraints pertaining to inadequate anti-retroviral medication for children.

In summary it is evident that children are a vulnerable group when it comes to testing and treatment. Aside from the challenges posed by their age and capacity to understand the implications of testing and treatment for HIV, there are also other factors relating to cases where children are orphaned and living without parents or a guardian. It is especially important then in light of these challenges that informed consent rules are followed as well as the provisions of the relevant legislation mentioned above when testing children for HIV. Pre-test counselling should also be an imperative so that children understand the testing process and the implications of a positive result. Where children do have parents or a guardian then informed consent must be obtained having regard to the ages stipulated in terms of the Children's Act.

4.8 HIV and Male Circumcision

It has been mentioned that HIV in sub-Saharan Africa is transmitted primarily through heterosexual contact and many scientists cited circumcision as a useful HIV prevention strategy.³⁵⁷ Although an effective prevention strategy for HIV, it must be understood that circumcision alone does not provide complete protection against HIV. Circumcision should be used in conjunction with other prevention measures to reduce the risk of transmission of HIV. This must also be done within the context of a human rights based approach.³⁵⁸

³⁵⁷ R Wamai „Male circumcision for HIV prevention: current evidence and implementation in Sub-Saharan Africa“ (2011) 14(49) *Journal of the International Aids Society* 2.

³⁵⁸ UNAIDS. Safe, Voluntary, Informed Male Circumcision and Comprehensive HIV Prevention Programming Guidance for decision makers on human rights, ethical & legal considerations (2007) P 2, 3. Available at http://data.unaids.org/pub/Manual/2007/070613_humanrightsethicallegalguidance_en.pdf Last accessed on 2014/08/07.

A human rights based approach would raise issues of informed consent and of particular importance is the capacity of children to consent to circumcision. A human rights based approach would ensure that:

- a) Accurate information concerning circumcision is provided to all people;
- b) The risks and benefits associated with the procedure are explained;
- c) Circumcision is accessible to all without discrimination; and
- d) Circumcision is carried out in a safe manner.³⁵⁹

At no stage should circumcision be mandatory and should always be carried out with the voluntary informed consent of the individual.³⁶⁰ Questions which arise in relation to children and circumcision revolve around the issue of consent. Can all male children be circumcised in order to protect them against HIV?

The Constitution protects the rights of the child and provides that the child's best interests are of paramount importance in all matters surrounding the child.³⁶¹ How does one decide if circumcision is in the best interests of all male children and can government make a ruling that male children should be circumcised to reduce the risk of HIV transmission?

The Children's Act provides that a child who is over the age of 16 years can consent to circumcision on his own provided he has been properly counselled.³⁶² A child who is under the age of 16 years can only be circumcised for religious reasons or for medical reasons on the recommendation of a doctor.³⁶³

Were a child over the age of 16 years to be coerced or compelled to undergo circumcision, such coercion or compulsion would be illegal and contrary to legislation. Doctors who perform a circumcision under such circumstances would in all likelihood be guilty of a criminal offence. He or she could also face disciplinary action by the HPCSA.³⁶⁴

³⁵⁹ *op cit* 4.

³⁶⁰ *op cit* 7.

³⁶¹ The Constitution Act 108 of 1996 s28.

³⁶² Children's Act 38 of 2005 s12 (9) (a) & (b).

³⁶³ Children's Act 38 of 2005 s12 (8) (a) & (b).

³⁶⁴ DJ McQuoid-Mason „Is the mass circumcision drive in KwaZulu-Natal involving neonates and children less than 16 years of age legal? What should doctors do?“ (2013) 103(5) *SAMJ* 284.

In summary the Constitution clearly protects the rights of children and although circumcision may be a wise preventative measure in curbing HIV transmission, it must be done within the confines of the rules provided for in the Constitution. Circumcision for children below the age of 16 years can only be done on the recommendation of a medical doctor and must be for medical or religious reasons. Circumcision for children over the age of 16 years must be done with voluntary informed consent and in conjunction with counselling.

4.9 Conclusion

This chapter has identified that the ethical and legal rules of informed consent are traced throughout the various sources of South African law as well as in the guidelines for HIV testing and counselling. Various types of testing have been discussed and the challenges with each type of testing have also been examined. Voluntary counselling and testing has not met with much success within the South African context and in its objective to reach as many people as possible in order to determine HIV status and provide treatment. Other options have been presented and it may seem that opt-out testing presents a better alternative for pregnant women, with fewer concerns and the ability to target a greater number of women presenting at health care facilities.

The rules of informed consent for testing of other vulnerable groups such as children and males for circumcision must also be observed bearing in mind that criminal sanction can be imposed on those who act outside the scope of the rules laid down in the Constitution.

Whilst this chapter touched on mandatory testing as a possible option for HIV testing for pregnant women, Chapter 6 will examine mandatory testing in further detail. Other exceptions to informed consent such as emergency treatment, therapeutic privilege, necessity, unauthorised administration, public health risk, and statutory provisions dealing specifically with HIV testing will be discussed in Chapter 5.

CHAPTER 5

EXCEPTIONS TO INFORMED CONSENT

5.1 Introduction

The previous chapters focused on the legal and ethical aspects of the rules of informed consent as well as informed consent in the context of HIV with reference to the guidelines set out in various sources of law. This chapter examines the instances when the rules of informed consent may be lawfully waived. There are several exceptions to informed consent. The exceptions which will be discussed in this chapter with reference to the Constitution, legislation and the common law are emergency treatment, public health risk, therapeutic privilege, necessity, unauthorized administration and mandatory testing.. These exceptions are instances when a person's right to privacy, autonomy and freedom of choice may be justifiably limited.³⁶⁵ In discussing the above exceptions it has been difficult to place them in neat categories as there is a degree of overlap among them. .³⁶⁶

The exceptions to informed consent have their place in law. Aside from mandatory testing, the other exceptions merit a cursory discussion within this chapter. Bearing in mind the title of this paper, mandatory testing will be introduced at the end of this chapter for the purposes of defining and recognizing it as an exception to informed consent. It will however be discussed in detail in Chapter 6.

5.2 Emergency Medical Treatment

For the purposes of this paper a distinction must be drawn between a person who seeks to enforce his or her right to emergency medical treatment and a person to whom emergency medical treatment is administered where such a person is unable to provide informed consent to treatment. This discussion centres on the latter category of persons although the former will be mentioned for purposes of defining emergency medical treatment.

³⁶⁵ Carstens & Pearmain *op cit* 888.

³⁶⁶ Criminal Law (Sexual offences and Related matters) Amendment Act 32 of 2007.

The Constitution³⁶⁷ as well as the National Health Act³⁶⁸ provides that no one may be refused emergency medical treatment. The Constitution also provides that everyone has a right to life.³⁶⁹

In *Soobramoney v Minister of Health KwaZulu-Natal*³⁷⁰ the court defined emergency medical treatment as a „dramatic sudden situation or event which is of a passing nature in terms of time that can be cured through medical treatment.“³⁷¹ McQuoid-Mason submits that emergency medical treatment will not be applicable to persons suffering from chronic incurable illnesses but rather to a situation where a person is faced with the sudden possibility of death or serious injury that results from an event.³⁷² Strauss provides that there are definitely circumstances when a doctor or other medical personnel will be legally bound to provide medical assistance to accident victims unless to do so would pose a threat of harm to the doctor or medical personnel.³⁷³ Rape survivors are also entitled to emergency medical treatment and the police should ensure that such treatment is provided to rape survivors immediately after the alleged offence. Failure to do so may have delictual liability implications for the police service.³⁷⁴

A person’s informed consent must be obtained prior to the administration of any medical treatment. There are situations however which arise when it is not possible for a doctor to obtain such consent. One such situation is when emergency medical treatment has to be given.

Emergency medical treatment is an exception to informed consent. Emergency medical treatment refers to a situation where a patient is treated without his or her consent having been obtained due to the fact that the patient is unable to give consent and there is the danger that death or irreversible damage to the patient’s health will result if he or she is not treated. The patient must not have previously refused consent to such treatment.³⁷⁵

³⁶⁷ The Constitution Act 108 of 1996 s 27(3).

³⁶⁸ The National Health Act s 7 (1)(e).

³⁶⁹ The Constitution Act 108 of 1996 s 11.

³⁷⁰ *Soobramoney v Minister of Health, KwaZulu-Natal* 1998(1) SA765 (CC).

³⁷¹ *Soobramoney v Minister of Health, KwaZulu-Natal* 1998(1) SA765 (CC) at 778; cf DJ McQuoid-Mason „Emergency medical treatment and „do not resuscitate” orders: When can they be used?”(2013) 103(4) *SAMJ* 223.

³⁷² DJ McQuoid-Mason „Emergency medical treatment and „do not resuscitate” orders: When can they be used?”(2013) 103(4) *SAMJ* 223.

³⁷³ SA Strauss *op cit* 90, 91.

³⁷⁴ D Mcquoid-Mason, A Dhali & J Moodley „Rape survivors and the right to emergency medical treatment to prevent HIV infection” (2003) 93 (1) *SAMJ* 42.

³⁷⁵ MA Dada & DJ Mcquoid-Mason *A-Z of Nursing Law* (2011) 63.

In linking emergency medical treatment to testing for HIV, the World Health Organisation Guidelines as well as HPCSA and SAMA guidelines provide that a person may not be tested for HIV without his consent except where testing is done for epidemiological purposes and is unlinked and anonymous.³⁷⁶ This may be in cases where blood is screened for transfusion purposes or for the manufacture of other blood products. UNAIDS and the WHO allow for mandatory testing only in instances where screening of blood is done for HIV and where there is screening of donors before procedures involving transfer of bodily fluids or body parts as in the case of artificial insemination, corneal grafts and organ transplants.³⁷⁷ A practical situation where these exceptions may qualify as a medical emergency could be for example where a transplant has to take place and the organ is only viable for a certain period of time.

In summary while informed consent is a pre-requisite for medical treatment, our law recognizes that there may be instances where emergency medical treatment may be administered to a patient without his informed consent. This is an exception to informed consent and is a valid defence for a doctor who may later face legal action for failing to obtain informed consent from the patient. The patient's life must have been in danger and the patient must be unable to consent to the medical intervention or treatment.

5.3 Public Health Risk

In instances where there is a risk to public health, the rules of informed consent may be relaxed. An example of a public health risk would be for example where an infectious disease breaks out which threatens the lives of many people.³⁷⁸ In *The Minister of Health of the Province of the Western Cape v Goliath Griesel* J granted an order authorizing the isolation and treatment of the respondents who had been diagnosed with highly infectious drug resistant tuberculosis on the basis that they posed a severe public health risk to their families and other members of the public. The respondents had refused to be isolated or treated. Griesel J cited Section 36 of the

³⁷⁶ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions: Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 8.1

³⁷⁷ WHO. Statement on HIV testing and counselling : WHO, UNAIDS re-affirm opposition to mandatory HIV testing (2012) Available at http://www.who.int/hiv/events/2012world_aids_hiv_testing_counselling/en/ Last accessed on 2014/10/25.

³⁷⁸ *The Minister of Health, Western Cape v Goliath* 2009 (2) 248 (C).

Constitution in his judgment and in justifying the order to isolate and treat the respondents in the interests of public health.³⁷⁹

It would be necessary for authorities to take preventative measures to prevent the spreading of the disease, for example the recent Ebola outbreak which poses a serious threat to society in general. Such preventative measures may mean quarantining those infected and also providing medical treatment to such individuals. Having to take these steps may imply that a person's right to privacy can be infringed if he or she is not willing to submit to treatment or quarantine.³⁸⁰ Will it be lawful to hold and treat someone against their will and without informed consent in order to protect the public from risk of infection?

International guidelines provide that an individual's right to liberty of movement may be restricted if provided for by law when necessary to protect public health or the rights and freedoms of others.³⁸¹

The Constitution provides that a person's rights contained in the Bill of Rights which include the right to privacy, the right to freedom as well as the right to bodily and psychological integrity, may be limited in terms of general application if it is reasonable and justifiable to do so in an open and democratic society, taking into account relevant factors.³⁸² These relevant factors are the nature of the right, the importance of the purpose of the limitation, the nature and extent of the limitation, the relation between the limitation and its purpose; and the less restrictive means to achieve this purpose.³⁸³ The qualification is that the limitation must be based on principles of human dignity, equality and freedom and taking into account all relevant factors.³⁸⁴

In light of the limitation in the Constitution it can be argued that there are competing interests at stake where a person's right to freedom must be balanced against the rights of the public as a

³⁷⁹ *The Minister of Health, Western Cape v Goliath* 2009 (2) 248 (C).

³⁸⁰ Carstens & Pearmain *op cit* 1000.

³⁸¹ UN International Covenant on Civil & Political Rights. Article 12 1.3 Available at <https://treaties.un.org/doc/Publication/UNTS/Volume%20999/Volume-999-I-4668-English.pdf> Last accessed on 2014/10/02.

³⁸² The Constitution Act 108 of 1996 s 36 (1).

³⁸³ The Constitution Act 108 of 1996 s 36 (1).

³⁸⁴ *Ibid.*

whole. The National Health Act provides that a health service can be provided to a patient without obtaining his or her informed consent if failure to treat such a person will result in a serious risk to public health.³⁸⁵ A duty is also placed on the Director General of Health to ensure that national health policy provides for the management and control of communicable diseases.³⁸⁶ This would mean that a person can be treated and quarantined without his consent in the event that there is a serious threat to public health. Obviously if a person refuses consent to treatment for an illness that does not pose a public health risk, he cannot be compelled to submit to treatment.

In light of the topic of this paper, it is necessary to consider whether HIV could ever be classified as a public health risk and whether such risk can allow for mandatory testing.

In *S v Makwanyane*³⁸⁷ the Constitutional Court pointed out that „the limitation of constitutional rights for a purpose that is reasonable and necessary in an open and democratic society, involves the weighing up of competing values, and ultimately an assessment based on proportionality.“³⁸⁸

Due to the nature of the transmission of HIV and that it is unlike contagious diseases such as Tuberculosis and Ebola which can be easily transmitted through casual contact, it may be difficult to justify mandatorily testing a person for HIV on the basis that it constitutes a public health risk. An isolated example may be in a case where a person willfully and sexually transmits HIV to many people or where for example a health care worker injects all male patients with infected needles since she was infected by a male partner. These examples may constitute a public health risk which justify mandatorily testing a person for HIV in terms of the provisions of the National Health Act which have been mentioned above. It must be borne in mind however that such testing will have to be reasonable and justifiable in terms of the constitution as it will amount to a limitation of the individual's rights to privacy and bodily and psychological integrity.

In summary informed consent rules may be relaxed where there is a risk to public health. An individual's constitutional rights may be limited in terms of Section 36 of the Constitution

³⁸⁵ The National Health Act s 7(1)(d).

³⁸⁶ Section 21(2)(k).

³⁸⁷ *S v Makwanyane* 1995(3) SA 391 (CC).

³⁸⁸ *S v Makwanyane* 1995(3) SA 391 (CC) at Paragraph 104; cf K Naidoo & K Govender „Compulsory HIV testing of alleged sexual offenders- a human rights violation“ (2011) 4(2) *SAJBL* 98.

provided that the limitation satisfies certain constitutional requirements. There is a duty on government to ensure that a national policy is in place to provide for the management of communicable diseases which pose a public health risk. Testing for HIV without consent may be carried out in terms of the National Health Act if it poses a risk to public health. Such testing will have to be reasonable and justifiable in terms of the Constitution.

5.4 Therapeutic Privilege

It has already been established that a doctor has a duty to inform his patient of the material risks in any intended procedure or medical treatment.³⁸⁹ The patient must have knowledge and appreciation of the proposed treatment or procedure, the risks associated with the treatment and the alternative options available before providing his or her informed consent to same.³⁹⁰

Strauss however, maintains that to insist that a patient be fully informed at all times might not always be in the patient's interest. Strauss is of the view that there might be instances where information given to the patient regarding the reality of his or her medical condition might cause the patient to become seriously depressed and may even deter the patient from consenting to treatment which may be necessary to heal the patient or relieve him or her of pain and suffering.³⁹¹

The practice of withholding the truth from a patient regarding his or her medical condition by a doctor is called therapeutic privilege. Therapeutic privilege is defined as:

The withholding of information from the patient which is considered to be a potential danger to the patient's well-being. Information is withheld during the consent process in the belief that its disclosure would lead to hardship or suffering of the patient.³⁹²

Therapeutic privilege therefore allows a limitation of the doctor's legal duty to disclose information by complying with the rules of informed consent.³⁹³

³⁸⁹ See Paragraph 2.3.2.

³⁹⁰ See Paragraph 2.4.1 (Note 66 above).

³⁹¹ SA Strauss *op cit* 18.

³⁹² K Hodkinson „The Need to Know –Therapeutic Privilege: A Way Forward“ (2013) 21 *Health Care Anal* 106.

The National Health Act allows for therapeutic privilege by providing that a health care provider must inform the user of his health status except in situations where there is substantial evidence to indicate that such disclosure would be contrary to the user's best interests.³⁹⁴

The Promotion of Access to Information Act also contains a similar provision where a request has been made to an information officer for access to the medical records of a person. If the information officer is of the view that disclosure of this information might cause serious risk or harm to the person requesting it then the officer must consult with a health practitioner for an opinion.³⁹⁵ If the medical practitioner is of the opinion that the person requesting the information might face mental or physical harm then the information officer can only give access to the records upon the requester proving to the information officer that sufficient arrangements have been made for the person's counselling to alleviate any harm he may be exposed to.³⁹⁶

In order to rely on the defence of therapeutic privilege the doctor will have to prove that:

- a) The facts and circumstances justify the use of the privilege;
- b) He was convinced that full disclosure would have a significant detrimental effect on the patient; and
- c) The exercise of the discretion was reasonable under the circumstances.³⁹⁷

In *VRM v Health Professions Council*³⁹⁸ the facts of which have been dealt with in Chapter 4, the plaintiff had been unaware that she was HIV positive during her pregnancy. Her doctor, the defendant had taken blood for an HIV test and had not informed her of the test for HIV or the results thereof prior to her delivery. In his defence the defendant claimed that due to the fact that she was a month away from delivering her baby he did not think it was in the plaintiff's best interests to advise her of her status. He also stated that he thought it would be cruel and heartless

³⁹³ LC Coetzee „Medical therapeutic privilege, a separate and independent defence *eo nomine*?’ (2004) 3 *TSAR* 464.

³⁹⁴ The National Health Act s 6 (1)(a).

³⁹⁵ The Promotion of Access to Information Act 2 of 2000 s 30 (1)(b).

³⁹⁶ Section 30 (3)(a).

³⁹⁷ WJ Morton „The Doctrine of Informed Consent Medicine and Law” 6(2)117-125 on 121; *cf* P Van Den Heever „Therapeutic privilege in the South African medical law” (1993) 83 *SAMJ* 911.

³⁹⁸ *VRM v Health Professions Council of SA and others* [2003] JOL 11944 (T).

to inform her that she was HIV positive and that informing her at that stage would not change anything.³⁹⁹

Although not raised as a defence, it is clear in this case that the doctor relied on the therapeutic privilege to justify his failure to inform the patient of her HIV status prior to delivery. In their discussion of the judgment Carstens & Pearmain are of the view that therapeutic privilege should only be used when the patient would suffer more harm than help from the disclosure and that it should not be used as an excuse to save the patient from hearing bad news about his medical condition.⁴⁰⁰ Carstens & Pearmain also speculate as to the choices that the plaintiff could have exercised had she been informed at an earlier stage of her HIV status. She would have been in a position to decide whether or not to terminate the pregnancy or whether or not to take steps to prevent mother-to-child transmission of HIV. She could also have attended counselling sessions to be better prepared for the possibilities following the birth of the child.⁴⁰¹

In summary, therapeutic privilege allows a doctor to withhold information about a patient's medical condition where disclosure may be to the patient's detriment. The National Health Act as well as the Promotion of Access to Information Act allow for therapeutic privilege as an exception to informed consent. The case of *VRM v Health Professions Council* highlights an instance where the doctor was not justified by using therapeutic privilege to withhold information from a patient about her HIV status.

5.5 Necessity

Necessity is defined as a situation where a person commits an act in order to protect another person's interest from harm or the interest of a third person from harm or the threat of harm. The harm must have commenced or be about to commence and cannot be avoided.⁴⁰²

The requirements for necessity are similar to that of unauthorized administration with the exception that with necessity the patient does not have to be incapable of consenting, the

³⁹⁹ *VRM v The Health Professions Council of South Africa* (2003) JOL 11944 T;cf Carstens & Pearmain *op cit* 985, 986.

⁴⁰⁰ *VRM v The Health Professions Council of South Africa* (2003) JOL 11944 T;cf Carstens & Pearmain *op cit* 991.

⁴⁰¹ Carstens & Pearmain *op cit* 991.

⁴⁰² Carstens & Pearmain *op cit* 909.

intervention does not have to be against his will and does not have to be in the patient's best interest⁴⁰³. There must be an emergency and the medical intervention must be in the best interests of society, such interest being of greater importance than the person's.⁴⁰⁴ It has been shown that a single dose of Nevirapine given to a baby can reduce the risk of mother to child transmission of HIV by 50%.⁴⁰⁵ This may be an example where a doctor may use necessity to justify administering potential life-saving treatment to a baby if the mother fails or refuses to consent to the administration of the treatment. Saving the life of a baby can also be argued to be in the interests of the preservation of society.

Unauthorised Administration

Unauthorised administration is defined as a situation where a person takes steps to protect the interests of another person who is absent, where the interests of such person are in danger. An example is where X's neighbour Y is away on holiday when a fire breaks out in the veld close to the house, threatening to damage Y's property. X breaks through a fence to gain access and put out the fire to save Y's property. Under normal circumstances, Y would face the possibility of prosecution for trespassing and malicious injury to property; however the principle of unauthorised administration affords him a valid defence.⁴⁰⁶

A doctor may also rely on the defence of unauthorised administration if he treats a patient who is in an unconscious state or in shock due to an accident and is unable to consent to treatment where he or she requires life-saving treatment.⁴⁰⁷ In order for such treatment to be lawful the doctor must prove that:

- a) There was a situation of emergency where the intervention was necessary to save the patient's life and could not be delayed in favour of obtaining the patient's informed consent.⁴⁰⁸ This means that there must be some grave danger threatening the life of the

⁴⁰³ MN Slabbert *Medical Law in SA* (2011) 145-147.

⁴⁰⁴ *Ibid.*

⁴⁰⁵ „Packaging HIV protection for infants“ Available at http://www.path.org/projects/nevirapine_pouch.php Last accessed on 2014/11/22.

⁴⁰⁶ SA Strauss *op cit* 92.

⁴⁰⁷ Carstens & Pearmain *op cit* 907.

⁴⁰⁸ *Ibid.*

patient and which requires immediate action to save the life of the patient.⁴⁰⁹ If it is possible to delay the action in favour of first obtaining the patient's consent, then this must be done.⁴¹⁰

- b) The patient must be incapable of consenting to the intervention.⁴¹¹ This means that the patient must be unconscious, delirious, in a coma or have certain awareness about his situation but be unable to rationally appreciate the situation or give informed consent.⁴¹²
- c) The intervention must not be against the patient's will or be prohibited.⁴¹³ If a person specifically refuses treatment even if it may be in his or her best interests, then the person's wishes must be respected. If medical treatment is administered contrary to the will of the patient, the doctor cannot later rely on the defence of unauthorised administration.
- d) The intervention must be in the patient's best interests.⁴¹⁴ This means that the treatment or intervention must be one which seeks to save the life of the patient or protects him or her from further harm.

In summary, in order for the doctor to be able to justify the lack of consent by using the defence of necessity and unauthorized administration, a doctor must prove that it was a situation of emergency and that he acted in the best interests of the patient by administering life-saving medical treatment which the patient was not able to consent to at the time when the treatment was administered. The medical treatment must be in the best interests of the patient or in the best interests of society.

⁴⁰⁹ SA Strauss *op cit* 93.

⁴¹⁰ *Ibid.*

⁴¹¹ Carstens & Pearmain *op cit* 908.

⁴¹² SA Strauss *op cit* 93.

⁴¹³ SA Strauss *op cit* 94.

⁴¹⁴ SA Strauss *op cit* 93.

5.6 Mandatory Testing

The word mandatory means required by law or rules.⁴¹⁵ HIV testing means administering a test to determine whether a person is HIV positive or HIV negative, usually through the use of a blood sample.⁴¹⁶ Mandatory testing for HIV therefore involves the testing of an individual as required by law.⁴¹⁷ Mandatory testing is also known as compulsory testing and it allows the law to limit the rights of individuals to bodily integrity by requiring HIV testing. It is often seen as a precursor for some other purpose such as the obtaining of employment, immigrating to another country, marriage or for accessing medical treatment.⁴¹⁸ An individual may face legal consequences should s/he fail to comply. Mandatory testing is also an exception to informed consent.

Whilst the other exceptions to informed consent which have been discussed above are important for a global understanding of informed consent, the focus of this paper is mandatory testing for HIV as an exception to informed consent. Mandatory testing policy can be implemented in various contexts and the aim is to examine the current legislation, policy and guidelines for HIV testing within these contexts. This will be done in Chapter 6.

5.7 Conclusion

This chapter has dealt with the exceptions to informed consent highlighting those instances when informed consent rules which are entrenched in our law, may be justifiably waived or relaxed. Exceptions such as emergency treatment, public health risk, necessity, and unauthorized administration were examined for a contextual understanding of instances when the rules of informed consent may be relaxed. Mandatory testing as an exception to informed consent was mentioned and defined but will be discussed in detail in Chapter 6. The current legislation, case law, policy and guidelines will be examined and analysed.

⁴¹⁵ C Soanes et al *Pocket Oxford English Dictionary* (2005) 551.

⁴¹⁶ D McQuoid-Mason & M Dada *A-Z of Nursing Law* (2011) 144.

⁴¹⁷ Available at <http://oxforddictionaries.com/definition/english/mandatory?q=mandatory> Last accessed on 03/10/2012.

⁴¹⁸ E Durojaye „Addressing Human Rights Concerns Raised by Mandatory HIV Testing of Pregnant Women through the Protocol to the African Charter on the Rights of Women“ (2008) 52(1) *Journal of African Law* 45.

CHAPTER 6

MANDATORY TESTING FOR HIV

6.1 Introduction

Chapter 5 dealt with the exceptions to informed consent. This chapter focuses on mandatory testing as an exception to informed consent with reference to legislation, case law and guidelines when such testing may be allowed. Particular emphasis is placed on statutory provisions in relation to the compulsory testing of alleged sexual offenders, and testing outside of sexual offences in instances such as employment testing, occupational exposure, and opt-out testing for pregnant women. Mandatory testing for HIV can be viewed as an incursion of a person's rights to privacy, as well as the right to bodily and psychological integrity.⁴¹⁹ The discussion on informed consent in the earlier chapters clearly defined informed consent rules which must be observed when testing for HIV.⁴²⁰ This chapter aims to investigate the instances when a person may be tested for HIV without obtaining his or her informed consent and whether mandatory testing in these instances can be legally justified. As mandatory testing has been introduced and defined at the end of Chapter 5, the discussion below focuses on the legal position of mandatory testing for HIV in various contexts.

6.2 Statutory Provisions - Sexual Offences

A court is not likely to grant an order for a person to be subjected to medical treatment against his or her will.⁴²¹ There are certain exceptional cases however when a person can be treated without consent in terms of a statutory provision for example, where a person is given psychiatric treatment in terms of a detention order, where a person is treated where failure to treat him or her would constitute a public health risk, or where a blood sample is taken in cases where a criminal offence has taken place⁴²²

⁴¹⁹ The Constitution Act 108 of 1996 s14 & s12(1)(b).

⁴²⁰ See Paragraph 4.3.

⁴²¹ Dada & McQuoid-Mason *Introduction to Medico-Legal Practice* (2001) 10.

⁴²² Carstens & Pearmain *op cit* 917, 918.

6.2.1 Criminal Law (Sexual Offences & Related Matters) Amendment Act 32 of 2007

South African society is plagued with extremely high levels of crime and in particular sexual crimes against women and children. The high level of HIV infection in South Africa has also presented cause for serious concern by government as well as the general public.⁴²³ A study done in 2009 indicated that 19,6% of men who had committed rape were HIV positive.⁴²⁴ This indicates that rape is a significant contributor in the spread of HIV infection. Although the number of reported rapes has decreased by 3% since 2008/2009 there have been 46 253 reported cases in 2013/2014.⁴²⁵ The Medical Research Council has estimated that only one in nine rapes are reported to the police, meaning that there are many more unreported cases.⁴²⁶

The high incidence of rape and HIV infection in South Africa as well as the needs of vulnerable persons such as women and children highlighted the need for statutory intervention. In response to these concerns, the Criminal Law (Sexual Offences & Related Matters) Amendment was promulgated in 2007.⁴²⁷

The Act repealed the common law offence of rape and replaced it with a new statutory offence that applies to all forms of sexual penetration.⁴²⁸ The Act also introduced new statutory offences for adults and new, expanded or amended sexual offences against children and mentally disabled persons.⁴²⁹ This discussion will focus primarily of the offence of rape and the provisions of the Act relating to rape, services for victims of sexual offences and compulsory HIV testing of alleged sexual offenders.⁴³⁰

⁴²³ K Naidoo & K Govender „Compulsory HIV testing of alleged sexual offenders- a human rights violation“ (2011) 4(2) *SAJBL* 95.

⁴²⁴ Rape in South Africa Prevalence. Available at <http://rapecrisis.org.za/rape-in-south-africa/> Last accessed on 2014/10/06.

⁴²⁵ ISS Crime Hub. Fact Sheet Explaining the official crime statistics for 2013/14/. Available at <http://www.issafrica.org/uploads/ISS-crime-statistics-factsheet-2013-2014.pdf> Last accessed on 2014/10/06.

⁴²⁶ Rape in South Africa Prevalence. Available at <http://rapecrisis.org.za/rape-in-south-africa/> Last accessed on 2014/10/06.

⁴²⁷ Criminal Law (Sexual Offences & Related Matters) Amendment Act 32 of 2007.

⁴²⁸ Criminal Law (Sexual Offences & Related Matters) Amendment Act 32 of 2007 (Objects of the Act).

⁴²⁹ *Ibid.*

⁴³⁰ Criminal Law (Sexual Offences & Related Matters) Amendment Act 32 of 2007 ss 28,30 & 31.

The main object of the Act is to provide certain services to victims of sexual offences which includes affording victims of sexual offences the right to receive Post Exposure Prophylaxis (PEP).⁴³¹ Rape is defined in the Act as :

Any person who unlawfully („A“) and intentionally commits an act of sexual penetration with a complainant („B“) without the consent of („B), is guilty of the offence of rape.⁴³²

The Act also makes provision for „compelled rape“ which is defined as :

Any person who unlawfully and intentionally compels third person („C) without the consent of („C“) to commit an act of sexual penetration with a complainant („B“) without the consent of („B“) is guilty of the offence of compelled rape.⁴³³

The Act provides that within 90 days after the commission of an alleged sexual offence any victim of such an alleged sexual offence or someone on the victim’s behalf may apply to a magistrate for an order that the alleged offender be tested for HIV and that the victim and the alleged offender be informed of the results.⁴³⁴ This discussion will only focus on the application by the victim. The victim’s application must state that :

- a) A sexual offence was committed against the victim by the offender;
- b) That the alleged offence was reported to the police;
- c) That the victim may have been exposed to the risk of HIV infection due to the sexual offence; and
- d) Less than ninety (90) days have elapsed since the alleged offence.⁴³⁵

Once the application has been made the magistrate must consider the victim’s case and if he or she is satisfied that there is *prima facie* evidence that a sexual offence has taken place, that the victim may have been exposed to body fluids of the offender and that no more than ninety (90) calendar days have passed from the date of the alleged offence⁴³⁶ then the magistrate must make

⁴³¹ Criminal Law (Sexual Offences & Related Matters) Amendment Act 32 of 2007 s 2(f).

⁴³² Section 3.

⁴³³ Section 4.

⁴³⁴ Criminal Law (Sexual Offences & Related Matters) Amendment Act 32 of 2007 s30 (1)(a)(i).

⁴³⁵ Section 30 (2) (a) (i)-(v).

⁴³⁶ Section 31 (3) (a)-(c).

an order that the alleged offender be tested for HIV and that the results be disclosed to the victim and the alleged offender.⁴³⁷

Upon granting of the order by the magistrate, it is the duty of the investigating officer to request a medical practitioner or a nurse to take two body specimens from the alleged offender.⁴³⁸

If an offender refuses to comply with an order that he submit to an HIV test, a warrant of arrest can be issued against him.⁴³⁹ If the alleged offender is found guilty he may be liable for a fine or imprisonment not exceeding three years.⁴⁴⁰

6.2.2 Anomalies surrounding the implementation of the Act

The passing of the Act, whilst noble in its intentions seems to have raised certain legal and ethical anomalies which are outlined below:

- a) Testing of an alleged offender for HIV during the window period may yield a false negative result even though the alleged offender might actually be HIV positive.⁴⁴¹ This may lead the victim to make personal choices about his or her lifestyle based on a false result. He or she could engage in unprotected sex and unknowingly infect his or her partner with HIV, if infected.⁴⁴² It would therefore be wise that the victim be informed or counselled of these risks when receiving post exposure prophylaxis treatment so that he or she can take the necessary precautions. The victim should also be tested again in three months to confirm the initial test results.
- b) Due to the nature of HIV and the intimate way in which it is transmitted, there is no foolproof way of determining whether or not the victim was infected by the offender during the commission of the offence? There may be a possibility that the victim was already infected at the time of the offence and was unaware of his or her positive

⁴³⁷ Section 31 (3) (c) (i).

⁴³⁸ Section 33 (1) (a).

⁴³⁹ Section 33 (3).

⁴⁴⁰ Section 38 (2).

⁴⁴¹ S Roehrs „Compulsory HIV testing of alleged sexual offenders: Role of the health care professional“ (2009) 27(10) *CME* 469.

⁴⁴² S Roehrs *op cit* 469.

status?⁴⁴³ It is questionable whether this „uncertainty“ provides good reason to infringe the rights of the alleged offender. In the event that the alleged offender does test positive for HIV it will be very challenging to prove beyond a reasonable doubt that he had infected the victim.⁴⁴⁴ These questions should thus raise concerns about the need to protect the rights of all citizens whether victim or offender and for all to be treated equally.

- c) Compulsory HIV testing of alleged sexual offenders can be viewed as a breach of the alleged offender's right to freedom, privacy, and bodily integrity.⁴⁴⁵ It can also be viewed as a breach of the alleged offender's right to remain silent and not to give incriminating evidence.⁴⁴⁶ The Constitutional limitation can be used to justify limiting the rights of the alleged offender in view of the high number of sexual assault cases taking place in South Africa. However one must take cognizance of the presumption that an accused person is innocent until proven guilty of an offence. To limit these rights would also mean that there will be no need to implement informed consent rules before testing the alleged offender for HIV. The Act also does not provide for pre- and post-test counselling to be administered to the alleged offender.⁴⁴⁷
- d) The Joint WHO/ILO guidelines on post exposure prophylaxis recommend that reporting of the sexual assault should not be a pre-requisite for receiving PEP or other services.⁴⁴⁸ Section 28 of the Act however provides that the victim can only access PEP if he or she lays a charge at the police service or reports the incident at a designated health establishment within 72 hours of the alleged offence. This provision may be too harsh and may not take into account the situation where a victim is raped by a known person and may be afraid to report the rape for fear of further violence or intimidation. Such a person may not be able to access PEP due to his or her failure to report the incident or lay a charge. The Department of Health guidelines do however provide to the contrary that

⁴⁴³ *Ibid.*

⁴⁴⁴ K Naidoo & K Govender „Compulsory HIV testing of alleged sexual offenders- a human rights violation“ (2011) 4(2) *SAJBL* 98.

⁴⁴⁵ S Roehrs *op cit* 470.

⁴⁴⁶ K Naidoo & K Govender *op cit* 98.

⁴⁴⁷ K Naidoo & K Govender *op cit* 98.

⁴⁴⁸ Joint WHO/ILO *Guidelines on post –exposure prophylaxis to prevent HIV infection* Paragraph 5.2.1.

the administration of PEP is an essential service for victims of sexual assault.⁴⁴⁹ This would seem to imply that despite the provisions of Section 28, victims of sexual assault will be afforded PEP regardless of whether they lay a charge or not against the alleged offender.

- e) The results of the HIV test are disclosed to the alleged offender, the victim as well as other role-players in the criminal proceedings such as the investigating officer, the prosecutor and the defence attorney. This is a further violation of the alleged offender's right to privacy and confidentiality. The alleged offender is also not privy to the HIV status of the victim.⁴⁵⁰ Once again, it needs to be determined whether such an invasion of the rights of the alleged offender is justifiable under the common law, the constitution and whether conflicting rights can be balanced.⁴⁵¹ It may be argued that the restriction of the alleged offender's constitutional rights is necessary in order for the police to administer justice, to investigate and prosecute crimes so that society as a whole is protected from harm.⁴⁵² McQuoid-Mason is of the view that the compulsory testing of sexual offenders without their consent is reasonable and justifiable provided that constitutional safeguards are observed with regard to confidentiality.⁴⁵³ On the other hand it may also be argued that although the taking of the blood sample from the alleged offender may not be extremely intrusive, once it appears that he has tested positive, it may be very difficult to guarantee confidentiality of this information. The victim on being informed of the status of the alleged offender may not be willing to respect the alleged offender's right to privacy and confidentiality.⁴⁵⁴ Naidoo and Govender have identified the following three questions that should be answered in order to determine whether the rights of the alleged offender can be justifiably restricted or infringed in favour of the rights of the victim:

⁴⁴⁹ South Africa Department of Health. National HIV Counselling and testing Policy Guidelines (2010) Paragraph 8.3.

⁴⁵⁰ TE Madiba & YA Vawda „Compulsory testing of alleged sexual offenders-implications for human rights and access to treatment“ (2010) 3(1) *SAJBL* 28.

⁴⁵¹ S Roehrs „Privacy, HIV/AIDS and Public Health Interventions“ (2009) 126 (2) *SALJ* 360.

⁴⁵² S Roehrs *op cit* 393.

⁴⁵³ D McQuoid-Mason „Compulsory HIV testing of alleged sexual offenders“ (2009) 99 (1) *SAMJ* 26.

⁴⁵⁴ K Naidoo & K Govender *op cit* 98.

- a) How invasive is the infringement of the rights of the accused?
- b) How persuasive is the justification for the infringement?
- c) Are less restrictive means available to promote the rights of the victim?⁴⁵⁵

Naidoo and Govender in answering these questions are of the view that although the HIV test is not extremely invasive, knowledge of the alleged offender's HIV status has no practical relevance to the treatment of the victim since PEP should be provided to the victim within 72 hours in any event to the victim.⁴⁵⁶ Further, as we have seen earlier, an initial negative test result is still not an absolute guarantee to the victim.

In summary, the high level of sexual crimes coupled with the high rate of HIV infection in South Africa has prompted government to pass the Criminal Law (Sexual offences & Related Matters Amendment which provides for the compulsory testing of alleged offenders in cases of sexual assault and the provision of PEP for the victim. The Act sets out the provisions that must be complied with for the granting of an order that the alleged offender be tested. The implementation of the Act however does present certain constitutional challenges and anomalies which might require that law and policymakers revisit these provisions in the future.

6.3 Mandatory Testing outside of sexual offences

Aside from the mandatory testing for HIV of alleged sexual offenders, other instances that involve mandatory testing for HIV such as pre-employment testing, testing in cases of occupational exposure to HIV and testing of pregnant women will also be considered. The testing of pregnant women will be discussed in order to examine whether there is a need to mandatorily test pregnant women for HIV.

6.3.1 Current legislation, policy and guidelines on mandatory testing for HIV in South Africa

The Constitution provides that every person has the right to privacy⁴⁶¹ as well as the right to bodily and psychological integrity which includes the right to security and control over their body.⁴⁶²

⁴⁵⁵ K Naidoo & K Govender *op cit* 99.

⁴⁵⁶ K Naidoo & K Govender *op cit* 99.

⁴⁶¹ The Constitution Act 108 of 1996 s 14.

The National Health Act provides that a health service may not be provided to a patient without his or her informed consent⁴⁶³ unless the provision of such health service is authorized in terms of any law or court order,⁴⁶⁴ or if failure to treat the patient will result in a serious public health risk.⁴⁶⁵ In the context of this discussion on mandatory testing for HIV, the term „health service“ will refer to an HIV test which implies that a person may not be tested for HIV without his or her informed consent. The legislation is quite clear on the rights of the individual as well as the narrow areas in which such rights may be limited. The aim of this discussion is to identify instances when mandatory testing may be legally justified and to examine the rules surrounding such testing. As compulsory testing for HIV in cases involving sexual offences has already been extensively discussed above under statutory provisions,⁴⁶⁶ further reference will not be made to it under mandatory testing, suffice to mention that it is also an instance when mandatory testing takes place in terms of a statutory provision.

The HPCSA and SAMA have also stipulated guidelines when a person's blood may be tested without consent. The HPCSA guidelines provide that a person may not be tested for HIV without his or her consent except where testing is done for epidemiological purposes and is unlinked and anonymous in accordance with the National Policy on HIV testing.⁴⁶⁷ SAMA guidelines provide that a person may only be tested without consent if such testing is in accordance with legislation or a court order.⁴⁶⁸ These guidelines will be mentioned in greater detail under employment testing and occupational exposure to HIV.

⁴⁶² Section 12 (1)(b).

⁴⁶³ The National Health Act 61 of 2003 s 7(1).

⁴⁶⁴ Section 7 (1)(c).

⁴⁶⁵ Section 7(1)(d).

⁴⁶⁶ See Paragraph 5.6.

⁴⁶⁷ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions :Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 8.1.

⁴⁶⁸ SAMA *Ethical and Human Rights Guidelines on HIV and Aids Part A: General Principles* (2006) Paragraph 2.1.

UNAIDS and the WHO do not endorse mandatory testing and have issued a statement in which they re-affirmed their opposition to mandatory testing.⁴⁶⁹ This statement provides that mandatory testing is only acceptable when :

- a) screening of blood is done for HIV and other blood borne infections where blood is to be used for transfusions or the manufacture of other blood products; and
- b) Screening of donors takes place before procedures involving transfer of bodily fluids or body parts as in the case of artificial insemination, corneal grafts and organ transplants.⁴⁷⁰

The statement further allows for routine or opt-out testing in high prevalence settings such as sites providing treatment for sexually transmitted diseases, tuberculosis, drug addiction, and antenatal and childbirth services.⁴⁷¹ Opt-out testing will be dealt with in greater detail in paragraph 6.3.2.3 below.

6.3.2 Testing with a court order

The general rule is that a person may only be tested for HIV without his or her informed consent if it is in terms of legislation or a court order. Pre-employment testing for HIV is provided for in the Employment Equity Act and is one of the instances when testing may take place with a court order. This also applies to occupational exposure through needle stick injuries which will be dealt with later.

6.3.2.1 Pre-employment testing

The International Labour Organisation (ILO) has recommended that employees should not be required to undertake an HIV test or to disclose their HIV status⁴⁷² and that any testing must be done on a voluntary basis and must not be coerced.⁴⁷³ The recommendations also provide that

⁴⁶⁹ WHO. Statement on HIV testing and counselling: WHO, UNAIDS re-affirm opposition to mandatory HIV testing (2012) Available at http://www.who.int/hiv/events/2012world_aids_day/hiv_testing_counselling/en/ Last accessed on 2014/10/25.

⁴⁷⁰ *Ibid.*

⁴⁷¹ *Ibid.*

⁴⁷² International Labour Organisation. Recommendation concerning HIV and AIDS and the World of Work (2010) (No.200) Paragraph 3(i) Available at <http://www.ilo.org/aids> Last accessed on 2014/10/25.

⁴⁷³ Paragraph 24.

workers, their families and their dependants should enjoy protection of their right to privacy and confidentiality in relation to HIV and AIDS.⁴⁷⁴

An employer is not permitted to request employees or job applicants to submit to an HIV test for the purposes of the job application or before being offered a promotion or special training.⁴⁷⁵ An employer may however wish to test an employee for a legitimate reason such as determining the prevalence of HIV in the workforce, to provide counselling, support and benefits to employees or to take measures to reduce the risk of infection in the workplace.⁴⁷⁶ In such instances, the Employment Equity Act provides that an employee or prospective employee can only be tested for HIV upon granting of an order by the Labour Court.⁴⁷⁷ The court may grant permission for the testing subject to certain conditions such as:⁴⁷⁸

- a) The provision of counselling to those being tested⁴⁷⁹;
- b) The maintenance of confidentiality of the test results and the status of the employee;⁴⁸⁰
- c) The period during which the tests may be authorized;⁴⁸¹ and
- d) The category or categories of employees who may be tested.⁴⁸²

In *Joy Mining Machinery v National Union of Metal Workers of South Africa & others*⁴⁸³ the employer applied to the Labour court for an order granting it permission to test employees for HIV. The reason that the employer provided for the need to administer the test was to plan an effective HIV and AIDS prevention strategy and to evaluate its training awareness programme. In arriving at its decision the court looked at whether the test was to be compulsory or voluntary, whether the employees would be able to give informed consent and whether pre-and post-test

⁴⁷⁴ Paragraph 3(h).

⁴⁷⁵ D McQuoid-Mason & M Dada *A-Z of Nursing Law* (2011) 142.

⁴⁷⁶ *Ibid.*

⁴⁷⁷ The Employment Equity Act 55 of 1998 s7.

⁴⁷⁸ Section 50 (4).

⁴⁷⁹ Section 50 (4) (a).

⁴⁸⁰ Section 50 (4) (b).

⁴⁸¹ Section 50 (4) (c).

⁴⁸² Section 50(4)(d).

⁴⁸³ *Joy Mining Machinery v National Union of Metal Workers of South Africa & others* 2002 (23) ILJ 391 (SALC).

counselling would be provided to the employees. The court authorised the employer to perform the HIV test on condition that such testing would be voluntary and anonymous.⁴⁸⁴

In *Irvin & Johnson Limited v Trawler & Line Fishing Union & Others*⁴⁸⁵ the employer also made an application seeking permission to test its employees for HIV on a voluntary and anonymous basis. The motivation to test their employees was to obtain information on the prevalence of HIV in the workforce to determine the potential impact of HIV/AIDS on the workforce and to plan to minimize the impact of illness and mortality on its operation. The employer also sought to implement support structures and preventative measures. The court decided that since the tests were to be administered on a voluntary basis, there was no need for an order to be granted in terms of Section 7 of the Employment Equity Act.⁴⁸⁶

Section 7(2) provides an important safeguard for the individuals' right to privacy. Due to the minimal risk of transmission of HIV in the workplace, the employer will have to have a compelling argument to obtain an order from the Labour Court to request that an employee or group of employees submit to an HIV test.⁴⁸⁷

In order to manage and regulate issues pertaining to HIV and AIDS in the workplace, the Department of Labour has also formulated the Code of Good Practice on Key Aspects of HIV and AIDS which provides guidelines for employers to ensure that employees are not unfairly discriminated against in the workplace.⁴⁸⁸ The Code provides that testing an employee for HIV may only take place if the Labour Court has deemed it justifiable.⁴⁸⁹ It also provides for instances where testing may take place by order of the Labour court which is referred to as authorised testing,⁴⁹⁰ and instances when testing for HIV may be done with the consent of the

⁴⁸⁴ *Ibid.*

⁴⁸⁵ *Irvin & Johnson Limited v Trawler & Line Fishing Union & Others* 2003(4) BLLR 379 (SALC).

⁴⁸⁶ *Ibid.*

⁴⁸⁷ O Dupper „Protecting the Rights of Workers living with HIV/AIDS: A South African Case Study“. Draft background paper, Inter-regional tripartite meeting on best practices in workplace policies and programmes on HIV/AIDS December (2003)15.

⁴⁸⁸ South African Department of Labour. Employment Equity Act No.55 of 1998 The Code of Good Practice on Key Aspects of HIV/AIDS and employment (2000) Paragraph 2.1.

⁴⁸⁹ Paragraph 5.3.3.

⁴⁹⁰ Paragraph 7.1.4.

employee. This is referred to as permissible testing and must take place at the initiative of the employee and with informed consent and pre- and post- test-counselling taking place.⁴⁹¹

In summary, pre-employment testing may only be carried out in terms of the provisions of the Employment Equity Act and in conjunction with international and national guidelines. The two cases which have come before the court have tested the application of Section 7 of the Employment Equity Act. There must be adequate justification for the granting of an order in terms of the Act in order for an employer to request an employee to submit to an HIV test. Confidentiality and counselling are important pre-conditions for testing.

6.3.2.2 Occupational Exposure - Needle stick Injuries

Testing a person's blood for HIV also has relevance where there has been occupational exposure to HIV as in the case of needle stick injuries to health care personnel. Needle stick injuries place the lives of health care personnel at risk and it is intended to examine the guidelines relating to situations where health care personnel encounter occupational exposure to HIV.

A needle stick injury occurs where a person usually a healthcare worker is pierced or sustains a cut from a sharp instrument that is contaminated with an infected patient's blood.⁴⁹² Healthcare workers are estimated to represent 12 percent of the working population worldwide and although many countries, including South Africa have guidelines in place to deal with such injury and exposure, there is a lack of data and information on the subject which makes it difficult to provide accurate estimates of the number of healthcare workers subjected to occupational exposure. It may therefore falsely appear that the number of injuries and subsequent infections is relatively low especially in sub-Saharan countries.⁴⁹³ It has been estimated that occupational exposures and infections will be more prevalent in developing countries where infection rate is higher and access to resources is limited.⁴⁹⁴ Surgeons face a greater risk of exposure to blood and

⁴⁹¹ Paragraph 7.1.5 (a) & (b).

⁴⁹² B Desalegn, H Beyene & R Yamada „Patients- to- healthcare workers HIV transmission risk from sharp injuries, Southern Ethiopia“ (2012) 9(1) *Journal of Social Aspects of HIV/AIDS* 2.

⁴⁹³ B Desalegn, H Beyene & R Yamada *op cit* 2.

⁴⁹⁴ EK Phillips, SS Pillay, P Goldberg & JC Jagger „Bloodborne pathogen exposure risk among South African surgeons“ (2011) *The South African Gastroenterology Review* 6.

body fluids than other health care personnel.⁴⁹⁵ It translates that there is a considerable risk to South African surgeons in view of the fact that prevalence of HIV is high and resources in public health facilities are limited. Practices and devices have been identified for use by surgeons and other health care personnel to reduce the possibility of exposure to blood and body fluids. These are for example the practice of double gloving, the use of blunt tip sutures to reduce suture needle injury rates, use of eyeglasses during surgery and the adopting of the hands free passing technique in theatre where the user places the sharp instrument in a container instead of handing it directly to the recipient.⁴⁹⁶

It is common cause that where a healthcare worker has sustained a needle stick injury from a source patient, an existing blood sample of the patient's may be tested with the patient's consent by asking the patient to consent to the use of an existing sample or the drawing of blood from the source patient if there is no existing blood sample. If there is an existing blood sample and the patient refuses to consent the blood sample may still be tested after informing the patient and ensuring privacy of the information.⁴⁹⁷ If there is no existing blood sample and the patient refuses to consent to an HIV test then the patient should be regarded as being HIV positive and the healthcare worker should begin prophylaxis treatment.⁴⁹⁸

Post Exposure Prophylaxis (PEP) treatment is an antiretroviral drug treatment that must be started within 72 hours after someone has been exposed to HIV. Whilst PEP is not 100% effective in preventing infection, evidence shows that taking a month long course of two to three combination antiretroviral drugs is effective in reducing the risk of infection.⁴⁹⁹ Many people however fail to complete the course of medication due to the side effects such as diarrhoea, nausea, vomiting, fatigue and headaches.⁵⁰⁰ Added to the unpleasant side effects, is the risk that the person can develop a drug resistance to antiretroviral medication if infected with HIV.⁵⁰¹

⁴⁹⁵ *Ibid.*

⁴⁹⁶ EK Phillips et al *op cit* 8.

⁴⁹⁷ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 8.2, 8.2.1.

⁴⁹⁸ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 8.2.2.

⁴⁹⁹ Post Exposure Prophylaxis PEP Available at <http://www.avert.org/post-exposure-prophylaxis-pep.htm> Last accessed on 2014/11/12.

⁵⁰⁰ *Ibid.*

⁵⁰¹ *Ibid.*

Bearing in mind the procedure that has to be followed for the testing of the blood of the source patient, as well as the side effects of PEP, it seems to be an invasion of the rights of healthcare personnel and somewhat inhumane to expose such persons to PEP without first determining whether it is indeed necessary. Health care personnel in South Africa are already expected to work under very stressful conditions and being exposed to HIV compounds the already stressful working environment and in some cases may lead to such persons suffering from post-traumatic stress disorder.⁵⁰² The health and safety of health care personnel in South Africa is compromised daily in health care facilities where resources are limited and the probability of exposure to infection higher than in other countries. To expose health care personnel to the disease and to expect them to take PEP without confirming the status of the source patient, appears to add insult to injury. Many safety devices have been developed to ensure infection prevention. Due to cost implications, these are however not readily available in South Africa and this limitation once again compromises the health and safety of South African health care personnel.⁵⁰³

The HPCSA guidelines provide that there cannot be a medical emergency where one can justify subjecting someone to an HIV test without consent in order to save another person's life.⁵⁰⁴ In the case of HIV it is very unlikely that there can ever be an emergency situation requiring that a person be submitted to an HIV test. Even in situations where the patient is under anaesthetic or in a coma, consent can be obtained when the patient wakes up or proxy consent can be obtained.⁵⁰⁵

While there are documented reports of needle stick injuries being sustained by healthcare workers, there has not been much documented evidence of such injuries being suffered by patients. One of the most recent and probably the first reported such incident took place in a public health facility. A pregnant woman attended a public health facility to be treated for gestational hypertension. Due to the unavailability of beds the patient had to wait in a corridor with other patients. Whilst waiting in the corridor the patient was injured when the intravenous

⁵⁰² L Ziady „The nurse's experience of exposure to possible HIV infection after an exposure/injury on duty" (2008) 12(1) *Professional Nursing Today* 22.

⁵⁰³ LE Ziady „Protecting South African healthcare personnel from blood-borne infection in the twenty-first century (2010)14(4) *Professional Nursing Today* 6.

⁵⁰⁴ Health Professions Council of South Africa. *Guidance for Good Practice in the Health Care Professions : Ethical Guidelines for Good Practice with regard to HIV Booklet 11* (2008) Paragraph 8.3.

⁵⁰⁵ TE Madiba, CL Jack & YA Vawda „Cold comfort for healthcare workers/ Medico-ethical dilemmas facing a healthcare worker after occupational exposure to HIV" (2011) 53 (6) *SA FAM Pract* 612.

needle of another patient became disconnected. The pregnant woman stepped on the dislodged needle and sustained an injury to her toe. The patient who was being treated with the intravenous needle was HIV positive. The pregnant woman received immediate medical attention for the needle stick injury and began antiretroviral treatment. Following the birth, the baby was also treated with Nevirapine and they both tested negative.⁵⁰⁶

While hospitals have policies in place to deal with needle stick injuries sustained by healthcare workers, this may be the first reported incident where a pregnant woman suffered a needle stick injury and Nevirapine was administered to a baby due to a needle stick injury sustained by the mother.⁵⁰⁷

The main reasons advanced for the injury taking place was the lack of available beds due to overcrowding at the facility. It may be time that a policy is developed to deal with needle stick injuries sustained by patients especially in countries such as South Africa where infection rate is high and public health facilities face a dire lack of resources, both medical and human.⁵⁰⁸

In summary legislation, guidelines and policy are clear that one cannot test a patient for HIV without his or her consent even in cases where needle stick injuries take place. If the source patient refuses consent to the test, then prophylaxis treatment must be administered immediately to the person suffering the injury. To test a person's blood without his consent would clearly amount to a breach of his right to privacy and bodily integrity. Such a breach will only be allowed if found to be reasonable and justifiable.

6.3.2.3 Mandatory or Opt-out Testing for Pregnant Women

The category of persons affected by opt-out testing for HIV in South Africa is pregnant women⁵⁰⁹. The testing of pregnant women for HIV was dealt with in Chapter 4 and is mentioned again in this chapter purely to examine whether mandatory testing should be implemented for pregnant women. Do the high rate of infection of pregnant women and the risk to the unborn

⁵⁰⁶ NC Ngene, CO Onyia & J Moodley „Needle stick Injury in a pregnant patient in an overcrowded hospital“ (2014) 15(2) *SAJHIVMED* 67.

⁵⁰⁷ NC Ngene, CO Onyia & J Moodley op cit 67.

⁵⁰⁸ NC Ngene, CO Onyia & J Moodley op cit 68.

⁵⁰⁹ See Paragraph 4.6.

child of being born HIV positive justify a mandatory or opt-out approach to testing? In Chapter 4 it was established that for various reasons a mandatory testing approach for pregnant women will not be feasible. An opt-out approach was considered a middle ground approach and less invasive in terms of a breach of the mother's rights to privacy, autonomy and bodily integrity. In this discussion it is intended to examine whether opt-out testing is actually a form of coercive or mandatory testing or whether opt-out testing can be justified in the South African HIV context. This discussion also highlights the importance of considering societal interests as well as the interests and welfare of the unborn child.

It is believed that about one third of pregnant women in South Africa are HIV infected with a vertical transmission rate of 25%.⁵¹⁰ Scaling up of PMTCT programmes has the potential to save 37 200 children from HIV infection annually.⁵¹¹ The disturbing evidence is that despite VCT interventions many women are still not accessing testing and treatment and whilst one may argue that it is the woman's right to exercise the choice to be tested and treated or not, one must also consider the impact that such a decision will have on the future of the unborn child and the implications of high infant infection and mortality rates for society. Advances in HIV testing and treatment suggest that a woman who participates in PMTCT can reduce the risk of transmission of HIV to her unborn baby from about 35% to 2%.⁵¹² One would assume that PMTCT would thus present a viable option for a pregnant woman who wishes to protect her unborn baby. Literature however suggests that barriers to testing and treatment still include a fear of stigma and discrimination, fear of lack of partner support, fear of a breach of confidentiality and mistrust of health workers.⁵¹³ These fears mean that many women who could access testing facilities are not doing so.

Technological advances in obstetric medicine such as ultrasonography and tissue sampling have come to view the foetus as a patient on its own instead of the traditional view of the foetus being

⁵¹⁰ M Selemogo „Evaluating the right to autonomy argument in the debate on coercive antenatal HIV testing in South Africa“ (2010) 3(2) *SAJBL* 63.

⁵¹¹ *Ibid.*

⁵¹² M Selemogo „The harm principle and the ethics of routine antenatal HIV testing in South Africa“ (2009)2(1) *SAJBL* 20.

⁵¹³ M Selemogo „Evaluating the right to autonomy argument in the debate on coercive antenatal HIV testing in South Africa“ (2010) 3(2) *SAJBL* 64.

viewed as an extension of the mother.⁵¹⁴ This may imply that a doctor should begin to regard the foetus as a patient as well.⁵¹⁵ If this is the case then the doctor has a duty to act in the best interests of the foetus as well as the mother. This view is in conflict with the legal position of the *nasciturus* fiction which provides that a foetus is only recognized as a legal subject if it is born alive. One may however argue that advances in medicine and technology may call for our law to evolve and to recognize the right of the unborn child not to be infected with HIV by his or her mother. This argument is in line with the German constitution which provides that everyone has the right to life, where the word „everyone“ is interpreted to include the unborn child.⁵¹⁶ The German constitution protects the rights of the unborn child and recognizes the foetus as an independent legal value.⁵¹⁷

It may be necessary to balance the right to autonomy of the mother against the right of the foetus to receive medical treatment (ARVS) in utero and to be born free of infection. Perhaps we can go a step further to state that these rights also impact the right of the general society to be made up of people who are healthy.⁵¹⁸ As has been stated earlier the primary deterrents to accessing VCT by pregnant women has been identified to be the fear of stigma, discrimination, possible partner violence or abuse, and the loss of livelihood. These fears have been found to be greater for women in developing countries where the rates of infection are higher and the access to treatment lower.⁵¹⁹ Whilst these are real concerns and fears it is suggested that instead of an emphasis being placed solely on the right of the pregnant woman to autonomy, the focus should be shifted to address these barriers to testing and treatment through education, awareness, pre- and post-test counselling and highlighting of the benefits of early detection and treatment. A practical way of addressing the fear of partner violence can be seen in some rural clinics in

⁵¹⁴ *Ibid.*

⁵¹⁵ Mattingly SS „The maternal-fetal dyad:exploring the two-patient obstetric model“ *Hastings Cent Rep* 1992,22:13-18; *cf* M Selemogo „Evaluating the right to autonomy argument in the debate on coercive antenatal HIV testing in South Africa“ (2010) 3 (2) *SAJBL* 64.

⁵¹⁶ Basic Law for the Federal Republic of Germany Article 2(2) Available at <http://www.constitution.org/cons/germany.txt>. Last accessed on 2014/11/12.

⁵¹⁷ German Constitutional Court Abortion Decision Available at http://groups.csail.mit.edu/mac/users/rauch/nvp/german/german_abortion_decision2.html.

⁵¹⁸ M Selemogo „Evaluating the right to autonomy argument in the debate on coercive antenatal HIV testing in South Africa“ (2010) 3(2) *SAJBL* 65.

⁵¹⁹ CB Smith, MP Battin, LP Francis & JA Jacobson „Should rapid tests for HIV infection now be mandatory during pregnancy? Global differences in scarcity and a dilemma of technological advance“ (2007) 7(2) *Developing World Bioethics* 96.

Kenya, where women's shelters have been added on to HIV services with the aim of protecting women from possible violence after discovering their HIV positive status.⁵²⁰ Even if a pregnant woman were to decline PMTCT, the nature of HIV is such that if she and her child were infected, the disease would eventually present itself thus making these fears a reality for both of them inevitably.⁵²¹

It is also argued that in view of the fact that PMTCT drastically reduces the risk of infection to the unborn child and can also prolong the life of the mother, this may justify implementing of an opt-out testing policy especially considering the fact that 20% of infected children will die in their first year of life.⁵²² An infected child suffers a negative impact to his or her health and welfare by having a compromised immune system, leading to illness and a shorter life-span as opposed to a child who receives ARV treatment before birth.⁵²³

In summary it is evident that the high rate of infection of pregnant women, the low uptake of VCT, the best interests of the unborn child, and the interests of society in general, justify the implementation of opt-out testing for pregnant women in a society, where barriers to testing and treatment have been adequately addressed and where women and their babies will be able to access treatment if found to be positive.

6.4 Conclusion

This chapter examined the legislative provisions, case law and policy guidelines on mandatory HIV testing in South Africa. South African legislation, policy and guidelines provide for mandatory testing in very limited and clearly defined instances. Each instance has been discussed by examining the legal position when testing may be justified. In the case of testing of alleged sexual offenders it is observed that the legislative provisions for testing present certain anomalies or challenges which may have to be addressed by lawmakers in the future. Testing in the employment context can only take place with a court order and even in cases where there is

⁵²⁰ M Selemogo „The harm principle and the ethics of routine antenatal HIV testing in South Africa“ (2009) 2(1) *SAJBL* 21.

⁵²¹ *Ibid.*

⁵²² *Ibid.*

⁵²³ *Ibid.*

occupational exposure, testing for HIV must be done with the person's consent. The discussion highlighted the plight of health care workers as well as patients in public health settings with limited resources. Whilst mandatory testing for pregnant women could not be endorsed, opt-out testing was identified as a middle ground option which may help to address high infection rates, low uptake of VCT as well as the interests of the unborn child. The final chapter of this paper will highlight the discussion contained in each of the chapters in this paper and will make recommendations regarding the doctrine of informed consent versus mandatory testing in the context of HIV.

CHAPTER 7

CONCLUSION AND RECOMMENDATIONS

7.1 Introduction

This paper investigated the legal and ethical implications of the doctrine of informed consent and mandatory testing for HIV. The rules of informed consent and mandatory testing were discussed in detail. The position with regard to mandatory testing in South Africa was discussed with reference to the legislative provisions for HIV testing. Challenges pertaining to testing and treatment for HIV, especially for vulnerable groups were highlighted. This investigation has enabled the writer to draw the conclusions and recommendations set out below.

7.2 Conclusions

Due to initial lack of political will on the part of government, South Africa, failed to launch an early and appropriate response to HIV/AIDS. As a result South Africa's prevention and treatment interventions were only intensified years after other countries. South Africa is thus faced with being the country with the highest rate of infection in the world. In 2013 South Africa faced the burden of 6,4 million people who were living with HIV. Only 2,3 million of these people were on ART.⁵²⁴ The infection rate of women is higher than that in men.⁵²⁵ This implies that women are a vulnerable group and should be prioritized.

The history of HIV/AIDS introduced the term „exceptionalism“ which defined the manner in which HIV testing was approached in the early days of the disease. Researchers, governments, and those infected or affected by HIV/AIDS debated whether the disease should be treated as any other disease affecting society or whether the nature of its transmission and the fear of stigma and discrimination required a more alternative and „exceptional“ response. It is apparent that the disease has been given exceptional status and it is concluded that this thinking and practice has fostered stigma and discrimination instead of overcoming it. As a result many do not access testing facilities due to such fears.

⁵²⁴ NP Simelela & WDF Venter „A Brief History of South Africa's Response to AIDS“ (2014) 104(3) *SAMJ* 251.

⁵²⁵ Fan, Conner & Villarreal *op cit* 119.

Legislation, case law and guidelines state that a person may not be tested for HIV without his or her informed consent. The introduction of voluntary counselling and testing (VCT) meant that a person had to be provided with pre- and post-test counselling during the testing process. Despite awareness campaigns and the availability of VCT facilities many people still do not know their status or access testing facilities. Extensive pre- and post-test counselling requirements place a further drain on time and resources in countries which are under-staffed and under-resourced. Medical practitioners only test a person for HIV if he or she exhibits symptoms of the illness or has a sexually transmitted disease.⁵²⁶ Exceptionalism, the lack of uptake of VCT and extensive informed consent requirements hinder progress in the fight against the disease.

Poverty, high unemployment rates, gender inequality, lack of resources, mismanagement and lack of accountability, poor staff morale and lack of adequate training in managing HIV are negative factors, requiring a dynamic response in order to provide more people with testing and treatment. The implementation of informed consent is often problematic in resource –constrained environments. Health care personnel do not always have the time or resources to counsel patients as they should and hence the informed consent process becomes purely academic.⁵²⁷ Cultural differences and language barriers often hinder the informed consent process. Superstitious beliefs and cultural taboos surrounding the transmission of the disease also impact whether a person will seek testing and treatment.⁵²⁸ Voluntary counselling and testing has been shown to be largely ineffective.

Opt-out testing has been introduced in South Africa but is not practiced in all medical settings. The challenges with opt-out testing is that it can be perceived as being tacitly coercive, causing the patient to be afraid to exercise his or her right to opt-out. Patients may also be afraid that their overall treatment may be compromised if they refuse an HIV test. Many youth and men do not access testing facilities and are unaware of their status.

⁵²⁶ See note 289.

⁵²⁷ Dhai & McQuoid-Mason Bioethics, *Human Rights and Health Law* 82.

⁵²⁸ Dhai & McQuoid-Mason *op cit* 83.

Pregnant women and their babies as well as children are identified as vulnerable groups of people in the HIV context and thus require an innovative response to combat high levels of infection.

Exceptions to informed consent have been discussed in Chapter 5 and mandatory testing for HIV is one of the exceptions which formed part of the main discussion in this paper in Chapter 6.. Current legislation allows for mandatory testing for HIV to satisfy pre-employment requirements, and testing in the case of sexual offences subject to strict requirements and the observance of counselling requirements for testing.

7.3 Recommendations

In light of the above conclusions drawn from this research, the following recommendations are made:

7.3.1 Multi-layered approach to HIV testing and treatment

South Africa should consider adopting a multi-layered approach to HIV testing and treatment. Testing should be opt-out testing for all people presenting themselves for medical treatment, not just pregnant women. The benefits of scaling up testing to offer opt-out testing to all persons seeking medical treatment will far outweigh the challenges and disadvantages provided that testing is carried out in a patient-friendly manner with proper regard for informed consent rules and in a non-threatening, non-coercive environment.

As part of this multi-layered approach South Africans should also be encouraged to make use of home testing kits and mobile testing sites. Where fears of stigma and discrimination still pose a threat, people who are able to afford home testing kits can make use of these as is done in the case of persons suffering from diabetes and high blood pressure. This will allow a person to be able to know his status in privacy. The concern that people should not use self-test kits without proper pre-and post-test counselling can be overcome by providing counselling information in the form of a pamphlet within the testing kit. Information in these pamphlets could include advice on where a person can seek counselling, website addresses of HIV/AIDs prevention organisations and the telephone numbers of counselling centres such as AIDS Helpline.

There are also other self- testing options such as supervised self-testing and community based self-testing which have emerged and which would address such fears and provide the person taking the test with the opportunity to be counselled as well. People testing in a community based testing environment may also be more confident to discuss cultural taboos and stereotypes and counsellors can provide important information to dispel these myths and stereotypes. Patients must however receive enough information about each option in order for them to make an informed choice. The days of VCT as the only available option have passed and technology has made new and more innovative options available which will help more people to know their status, access treatment and make behavioural changes.

The options of mobile testing facilities and home testing options also present a solution for men and youth who have been reluctant to access VCT sites. It is recommended that persons utilizing alternative options must also be provided with the necessary information either in the form of information pamphlets or media campaigns to sensitize and inform the public on the options available to them. HIV/AIDs awareness programmes in communities and schools should also inform and educate people on these types of testing options. The benefits of the scale up of this kind of testing in addition to opt-out testing is that more people will access treatment if they are aware of their status and more people will make behavior modifications which will in the long term reduce infection rates. More people will thus be able to live longer healthier lives which will go some way to alleviating the cost burden on the state. More parents will also be healthy enough to take care of their children thus lowering the number of orphans that the government has to provide for in terms of health and social welfare.

The concern that arises is whether home testing kits will be affordable for the ordinary South Africans. If a person cannot however afford a self-testing kit, he or she still has the option of mobile testing, VCT or opt-out testing and the more that we treat testing as routine and normal rather than exceptional, the more likely it will be that fear of stigma and discrimination will become a thing of the past. Issues of poverty, unemployment and gender inequality require an in-depth, long term governmental response which will also contribute to stemming infection rates. Embracing these new approaches to testing will obviate the need to consider mandatory testing

as an option. Mandatory testing will not be necessary as people will recognize the value of testing as something routine which will also enable them to access treatment if necessary.

The recommendations made above are also applicable to vulnerable groups such as pregnant women and children who will benefit from these options as well. Early diagnosis and treatment can improve the quality of life of a pregnant mother and drastically reduce the risk of transmission to an unborn child. A pregnant woman who is afraid of partner violence or possible stigma and discrimination from family and community members has the option to self-test with privacy and make an informed decision regarding the continuation of her pregnancy. Information in these self-testing kits as well as at opt-out and mobile testing sites should also provide women with information on places of safety and legal services available to them should they fear violence or abuse.

7.3.2 Simplifying the informed consent process without compromising patient autonomy

Unfortunately South Africa does not have the privileges of better resourced countries and therefore it may be time to simplify issues of informed consent without compromising autonomy and decision making on the part of the patient. Simplifying the informed consent process in a non-coercive environment will help to provide more people with access to testing and treatment in a shorter space of time. It is recommended that medical professional bodies examine ways in which the informed consent process can be simplified without compromising the patient's rights to autonomy and self-determination. Perhaps the screening of pre-recorded DVDs in healthcare settings may help to save time, inform more people and address issues of language, literacy or cultural diversity since DVDs can be presented in different languages depending on where the facility is located. Social media platforms should also be more extensively utilized to inform and educate those who have access to these communication mediums especially the youth. Pupils in schools and students at tertiary education institutions can be invited by the institution's counselling centres to sign up for a facebook page that gives information on HIV awareness, testing options and counselling available. In this way youth have the option to view this information in a non-threatening and supportive environment.

7.3.3 Mandatory testing does not represent a solution for South Africa's HIV challenge

Mandatory testing for HIV other than in the instances currently defined in legislation is not recommended as it represents a violation of human rights and freedoms and is not the solution to South Africa's problem of high infection rates. Mandatory testing means that a patient will have no option to opt-out and cannot be justified. Fears that mandatory testing will deter rather than encourage people to test is a possibility that South Africa cannot afford, especially with its high infection rates. The implementation of mandatory testing provisions in South Africa will be counter-productive and will result in a shift in focus, where NGO's and HIV interest groups may motivate and litigate for government to amend such discriminatory provisions as was done in the TAC case. Valuable time will be lost where focus, energy and resources could be used to reduce infection rates in more appropriate ways. It is recommended that in the South African context, opt-out testing for all persons seeking medical treatment presents a more acceptable middle-ground approach instead of oppressive and controversial mandatory testing provisions.

Mandatory testing can only be regarded as ethical and lawful in situations where legislation allows it for example for employment reasons, in the cases of sexual offences or in the narrowly defined instances where screening of blood or donors is necessary in order to conduct transfusions or perform transplants. Testing of pregnant women in order to protect the life of the unborn foetus and in cases where there is occupational exposure to HIV may be two areas where law and policymakers consider whether an HIV test can be mandatorily administered. Due to the large number of infected pregnant women in South Africa as well as the very real threat of occupational exposure in our resource constrained health facilities, these two focus groups may be worth examining in greater detail to determine whether mandatory testing can be implemented. Testing under these circumstances will however mean a careful balancing of the rights of all interested parties as well as being able to justify the limitation of the rights of affected parties in terms of the Constitution.

HIV/AIDS, as with influenza, the plague and other epidemics that have infiltrated society since time immemorial has caused hysteria, fear and differing social and governmental responses. It has claimed many lives, caused much pain and suffering for countless human beings across the planet. It is a disease that unites the world in a common fight although geography, numbers and

cultural factors often determine responses to the disease. HIV/AIDS has been prevalent in society for almost 30 years. As technology advances, and medical science works rapidly to find a cure, thinking and attitudes towards the disease and the issues surrounding it must also evolve to achieve the common global goal which is to ensure that infection rates are reduced and that access to treatment becomes a reality for all.

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